

# **Wheelchair Prescription in the Western Region of the Eastern Cape**

by  
Svenje Duffield

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Promoters: Dr Marianne Unger  
Ms Surona Visage

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## ABSTRACT

**Background:** Access to wheelchairs is considered a basic human right. Wheelchairs enhance function, improve independence, and enables persons with disabilities to successfully live in the community. An inappropriate wheelchair may however limit function rather than promote it. Achieving an ideal match between user and technology, however is challenging. A recent audit in the Eastern Cape revealed that standard folding frame type wheelchairs were predominantly being issued and waiting list for wheelchairs is long. The need for investigation into prescription practice, from the perspective of both prescribing therapists as well as wheelchair users, was identified.

**Aims:** To describe wheelchair prescription practice in the public sector of the Eastern Cape; and to determine whether the wheelchairs being issued address the psychosocial needs of users.

**Study design:** A descriptive mixed-method cross-sectional study design was used. Quantitative and qualitative data from questionnaires and functional wheelchair skills tests of wheelchair users (Phase 1) and from semi-structured interviews with prescribing therapists (Phase 2) was used to describe prescription practice and investigate the psychosocial needs of wheelchair users.

**Methods:** A small sample of convenience according to home address was obtained that included 30 users (15 from a rural; 15 from a semi-rural setting). The Psychosocial Impact of Assistive Devices Scale (PIADS) questionnaire, Functioning Everyday with a wheelchair (FEW/FMA) scale and a self-compiled wheelchair specifications checklist (WSC) were used to determine user functionality and level of satisfaction with the wheelchair. Purposive sampling was done to identify the therapists that had prescribed the wheelchairs for the participants in the first phase of the study. A semi-structured interview was used to determine prescription practice including perceived barriers of wheelchair prescription with ten prescribing therapists.

**Data analysis:** Qualitative data was analysed deductively and frequency of responses tabulated. Quantitative data was summarised as means and standard deviations and subgroup analysis comparisons were done using the Chi-square test and relationships between variables investigated using Pearson/ Spearman correlation or ANOVA. A  $p < 0.05$  was deemed significant.

**Results:** Eighty three % of wheelchairs issued were urban wheelchairs. These are generally perceived by users as sufficient to address their psychosocial needs regarding mobility and transport, however, seem to fail users in terms of accessibility and independence within their rural/ semi- rural environment. According to the WSC scores, peri-urban wheelchairs were found to be more appropriate for the users than urban wheelchairs ( $p < 0.01$ ). No significant relationships were found between wheelchair fit, use of a cushion, occurrence of pressure sores and self-perceived psychosocial needs in this sample. The users experienced most difficulty with outdoor mobility (57% needed full assistance) and transport (63% needed full assistance) within their current wheelchairs.

Ten prescribing therapists participated in the study. Most valued appropriate seating, are knowledgeable regarding prescription practice, but reported several barriers to this practice including budget restraints (90%), time to delivery (100%) and lack of training (40%). The need for more appropriate wheelchair designs to suit multi- level manoeuvrability of persons in rural/ semi-rural environments was also reported (60%).

**Conclusion:** The results of this study show that wheelchair prescription in the Western Region of the Eastern Cape (WRoEC) has various challenges. Although the wheelchair users were mostly satisfied with their wheelchairs, this study identified areas for improvement in the users' functioning, postural support and biomechanics within their wheelchairs, especially as it relates to their home environment. There is scope for improvement of wheelchair delivery to persons in the WRoEC – from on-going training of therapists and clients to more appropriate wheelchair designs for persons in rural settings. Further research in this field is recommended.

## ABSTRAK

**Agtergrond:** Toegang tot rolstoele word as 'n basiese mensereg geag. Rolstoele dra by tot verbeterde funksionaliteit, groter onafhanklikheid, en bemagtig mense met gestremdhede om suksesvol in die gemeenskap te lewe. Nietemin, 'n onvanpaste rolstoel mag funksie beperk eerder as om dit te bevorder. Om die ideale pas tussen rolstoel gebruiker en tegnologie te vind is uitdagend.'n Onlangse oudit in die Oos- Kaap het getoon dat standaard vou-raam tipe rolstoele oorwegend uitgereik word, en dat die waglys vir rolstoele lank is. Die gaping vir verdere ondersoek rakende voorskrif praktyk, vanaf beide die perspektief van die terapeute wat voorskryf asook rolstoel gebruikers, is geïdentifiseer.

**Doel:** Om rolstoel voorskrif praktyk in die publieke sektor van die Oos- Kaap te beskryf; en om vas te stel of die rolstoele wat uitgereik word die psigososiale behoeftes van gebruikers adresseer.

**Studie Ontwerp:** 'n Beskrywende gemengde metode deursnee studie ontwerp is gebruik. Kwantitatiewe en kwalitatiewe data van vraelyste en funksionele rolstoelvaardigheds toetse van rolstoel gebruikers (Fase 1) en van semi- gestruktureerde onderhoude met voorskrywende terapeute (Fase 2) is gebruik om voorskrif praktyk te beskryf en om die psigososiale behoeftes van gebruikers te ondersoek.

**Metodes:** Dertig rolstoel gebruikers (15 van 'n landelike; 15 van 'n gedeeltelik- landelike opset) het deelgeneem in die studie. Die PIADS vraelys, "Functioning Everyday with a Wheelchair" (FMA/ FEW) skaal en 'n self-opgestelde rolstoel spesifikasie kontrolelys (WSC) is gebruik om gebruiker funksionaliteit en tevredenheid met die rolstoel vas te stel. 'n Semi- gestruktureerde onderhoud is gebruik om rolstoel voorskrifpraktyk insluitend persepsies van beperkinge tot die voorskrifte van rolstoele vas te stel onder tien terapeute.

**Dataverwerking:** Kwalitatiewe data is deduktief geanaliseer en getal response is getabuleer. Kwantitatiewe data is opgesom as gemiddeldes en standaardafwykings en subgroep analise vergelyking is gedoen deur middel van die Chi- square toets. Verhoudings tussen veranderlikes is ondersoek deur middel van die Pearson/ Spearman korrelasie/ ANOVA.  $P < 0.05$  is as statisties beduidend aanskou.

**Resultate:** Drie-en-tagtig % van die uitgereikte rolstoele was landelike rolstoele. Hierdie stoele word oor die algemeen deur gebruikers ervaar as genoegsaam om hulle psigososiale behoeftes rakende vervoer en mobiliteit te bevredig, maar skiet nietemin tekort as dit kom by

toeganklikheid en onafhanklikheid binne hulle landelike-/ semi- landelike omgewing. Volgens die WSC resultate, is die semi- landelike rolstoele meer toepaslik vir die gebruikers as die stedelike rolstoele. Geen merkwaardige verhoudings is gevind tussen rolstoel pas, gebruik van kussing, drukserie en persepsie van psigososiale behoeftes nie. Die gebruikers het die meeste gesukkel met buitemuurse mobiliteit (57% het volle bystand benodig) en vervoer (63% het volle bystand benodig) in hulle huidige rolstoele.

Tien terapeute het aan semi-gestruktureerde onderhoude deelgeneem. Daar is bevind dat hulle korrekte “seating” waardevol ag, kundig is rakende voorskrif praktyk, maar het talle beperkinge geïdentifiseer in die praktyk insluitend: begrotings beperkings (90%), tyd tot aflewering (100%) en tekort aan opleiding in dié veld (40%). Die behoefte aan meer toepaslike rolstoel ontwerpe om multi- dimensionele beweeglikheid van persone in landelike/ semi- landelike omgewings te verseker, is ook vasgestel (60%).

**Gevolgtrekking:** Die resultate van hierdie studie toon dat die voorskrif van rolstoele in die Westelike streek van die Oos- Kaap (WSvOK) vele uitdagings het. Alhoewel die rolstoel gebruikers grotendeels tevrede was met hulle rolstoele, het hierdie studie areas vir verbetering geïdentifiseer in die gebruikers se funksionaliteit, posturale ondersteuning en biomechanika in hulle rolstoele, veral soos dit van toepassing is op hulle tuis omgewing. Daar is ruimte vir verbetering vir rolstoel lewering aan persone in die WSvOK; vanaf deurlopende opleiding vir terapeute en gebruikers, tot meer toepaslike rolstoel ontwerpe vir persone in landelike gebiede. Verdere navorsing in dié veld word aanbeveel.

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## GLOSSARY

**ASSISTIVE TECHNOLOGY:** ‘any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities’ (‘Technology-related assistance of individuals with disabilities act of 1988’ (PL 100 ± 407)).

**WHEELCHAIR:** ‘a device providing wheeled mobility and seating support for a person with difficulty in walking or moving around.’ (WHO Guidelines for the provision of manual wheelchairs in less resourced settings, 2008)

**APPROPRIATE WHEELCHAIR:** ‘A wheelchair is appropriate when it meets the user’s needs and environmental conditions; provides proper fit and postural support; is safe and durable; is available in the country and can be obtained and maintained and services sustained in the country at an affordable cost.’ (WHO, 2008)

**POSTURAL MANAGEMENT:** “The use of any technique to minimize postural abnormality and enhance function” (Farley et al 2003)

**PSYCHOSOCIAL:** involving both psychological and social aspects of one's life, and relating the social conditions to mental and emotional health ([psychosocialhealth.tripod.com/id2.htm](http://psychosocialhealth.tripod.com/id2.htm)).

**URBAN AREA/ ENVIRONMENT:** Of, pertaining to, or designating a city or a town. An urban area is characterized by higher population density and vast human features in comparison to areas surrounding it (Dictionary.com).

**PERI-URBAN/ SEMI- RURAL AREA/ ENVIRONMENT:** Immediately adjoining urban areas i.e. between the suburbs and the countryside, with characteristics of both urban and rural areas (ALLwords.com).

**RURAL:** the population living in towns and municipalities outside the commuting zone of larger urban centres (i.e. outside the commuting zone of centres with population of 10,000 or more). A rural area can be defined as an area that is remote and/ or underserved with limited infrastructure and resources. It mainly consists of countryside and farms (Du Plessis et al, 2001).



## ABBREVIATIONS

- WHO:** World Health Organisation.
- PT:** Physiotherapist/ Physical Therapist.
- OT:** Occupational Therapist.
- WC:** Wheelchair.
- PIADS:** Psychosocial impact of assistive device scale.
- AD:** Assistive Device.
- SA:** South Africa.
- EC:** Eastern Cape.
- WRoEC:** Western Region of the Eastern Cape.
- WSC:** Wheelchair Specifications Checklist.
- FEW:** Functioning Everyday with a Wheelchair.
- FMA:** Functional Mobility Assessment.
- HP:** Health Professional.
- HCC:** Health care clinic.
- PI:** Principal Investigator.
- Q:** Questionnaire.
- DoH:** Department of Health.
- QoL:** Quality of Life.
- WCPG:** Western Cape Provincial Government.
- ICF:** International Classification of Functioning.
- DPSA:** Disabled People South Africa

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# *Chapter 1*

## **INTRODUCTION**

The ability to independently move from one place to another has been described as one of the vital needs of humanity (Wagener & van der Spek, 2006). For those with physical disabilities however, this ability is often seen as a privilege. Despite the availability of mobility or other assistive devices enabling persons with disabilities to achieve independence, many persons living with mobility limitations, especially those living in under-resourced areas and/or countries still have limited or even no access to these devices (Borg, Lindstrom & Larsson, 2009).

Losing the ability to mobilize independently represents the greatest restriction to participation in life situations experienced by individuals with a spinal cord injury (SCI) and/ or other impairments of the lower limbs. To overcome this loss and enable the individual to engage in valued activities and life roles, a wheelchair might be required. The importance of the wheelchair in the life of these individuals cannot be overstated. For many, the manual wheelchair is their key to taking part in social, leisure and community activities (Bell & Hinojosa, 1995). Although a wheelchair can enable an individual to participate in social and community life, it can also influence the extent and quality of that participation (Davolt, 1996).

This chapter briefly provides a background to disability, wheelchairs and the need for an appropriate wheelchair and the importance of the psychosocial impact that wheelchairs have on persons with disabilities' lives. It also gives a brief outline of South African and international policies and documents on how wheelchairs should be prescribed (WHO, 2008; UN, 2006b; DoH, 2003). Wheelchair prescription practice in the Eastern Cape is briefly described leading to the motivation for undertaking the current study.

## 1.1 Background to the study

### 1.1.1 *Disability and disability approaches*

Disability is contextual in nature and the experience of disability differs vastly between various individuals due to the nature of impairment and the impact of contextual factors. In addition, definitions of disability have been subject to cultural differences and changes over time (WHO, 2001, McEwan & Butler, 2007). The most important disability approaches as they relate to this study is the medical and social disability approaches. Within the **medical approach** disability is defined as a disease or as a deviation from what society considers as normal – it is something that must be cured and is unacceptable. People with disabilities are looked down on (biologically and psychologically) and are seen as unable to make decisions for themselves, weak and dependant. Their physical shortcomings define what type of quality of life they will be able to achieve. This approach therefore often leads to exclusion from society (DPSA, 2004; Mackelprang, 2010). The **social approach** defines disability as the result of society's failure to provide appropriate services. The fault is seen to lie with social organizations in society – within which the needs of disabled people are not adequately accounted for. According to this approach, society has isolated disabled people through the establishment of closed institutions such as so called "special schools" and sheltered training workshops (Campbel, 2002; Tregaskis, 2002; DPSA, 2004; Watermeyer, 2006; Mackelprang, 2010). The social approach forms the basis of disability policy in South Africa (Office of the Deputy President, 1997, DoH, 2000). However, neither these two approaches fully encompass the complexity of disability, since both the impairment and the environment impact on disability.

The International Classification of Functioning, Disability and Health (ICF) is a classification of human **functioning** and **disability**. According to the ICF a complex interaction exists between the functioning of the body and the structural integrity of the body (impairments), his ability to do daily tasks (activity and participation) as well as contextual factors (environmental and personal) – and this is how a person's ultimate ability (their function and disability) is determined. Furthermore, disability and function is influenced by society imposing certain restrictions on persons with disabilities. It therefore includes an element of discrimination – physical and social barriers limit the opportunity of those with impairments to partake in everyday community life. According to the ICF, in order to live independently with a disability, a person might need certain resources and supports such as attendant care,

assistive devices such as wheelchairs and other adapted equipment (WHO, 2001). It is therefore vital to consider a person's socio-cultural context in understanding the concept of disability. Thinking has recently changed from describing - and in doing so stigmatizing - disability as a disease, to understanding disability as a complex relationship between a person's environment, their functional limitations and society's attitude (Brickenbach et al., 1999; WHO, 2011; Chaves, Boninger, Cooper, Fitzgerald, Grey & Cooper, 2004).

It is estimated by the recent *World Report on Disability* (WHO, 2011) that more than a billion people -  $\pm 15\%$  of the world's population - live with some form of disability. The World Health Organisation (WHO) reports following a Health Survey conducted in 69 countries in 2002 (WHO, 2011) that 18.6% of adults report having moderate, severe or extreme difficulty related to moving around. Similar statistics are reported by Mont (2007) which showed that one in five people living in India, Fiji, Indonesia, the Philippines or Mongolia have at least some difficulty, and one in twenty people experience severe difficulty walking or climbing stairs. According to the national census conducted in 2011, five percent of South Africa's population reported using an assistive device related to mobility specifically, 3.5% of the population reported difficulty with walking and climbing stairs and 2.3% of these were using wheelchairs to mobilise (Statssa, 2011).

Disability can be reduced significantly by adapting the environment to be more accessible, or by developing a person's abilities. The correct assistive device such as the appropriate wheelchair may also assist a disabled person in developing independence and skills to achieve activities of daily living. Assistive devices are therefore crucial in minimizing disability (Øderud, Brodtkorb, & Hotchkiss, 2004).

### **1.1.2 The need and the role of wheelchairs in persons with disabilities lives**

Assistive technology has been used by people with disabilities to facilitate the return to as many pre-injury activities as possible (Fuhrer, Jutai, Scherer & deRuyter, 2003). A specific form of assistive technology that is often used to achieve this is wheelchairs. Wheelchairs are used to enhance function, to improve independence, and to enable a person to successfully live at home and in the community (Borg, Lindstrom & Larsson, 2009; Greer, Brasure & Wilt, 2012). A wheelchair may however be perceived as negatively impacting a person's life if it does not enable him/her to participate fully in social and community activities (Scherer & Cushman, 2001; Smith, 1996). As seen in the ICF classification, for a user to be functional

within a wheelchair, there needs to be interaction between the wheelchair, the environment and the activity being performed (Routhier, Vincent, Desrosiers & Nadeau, 2003). Therefore a certain fit is required between the person and the wheelchair that is specific to the environment where the wheelchair is to be used, in order to ensure a positive psychosocial impact on the user in all activities of daily living (Scherer, 2002). A wheelchair that does not match the needs, abilities or preferences of the user, or is inappropriate for the environment in which it is being used, is likely to limit function rather than to promote it. Achieving an ideal match between wheelchair user and wheelchair technology, however, is as difficult as it is important (Di Marco, Russel & Masters, 2003).

### ***1.1.3 The psychosocial impact of a suitable/ unsuitable wheelchair***

The psychosocial impact of an assistive device refers to the impact that the device has on the user's quality of life – to what degree the device enables the person to participate in activities of daily life that are specifically important to them (Day & Jutai, 1996). In a study by Chaves et al. (2004), the data indicated that patients psychosocially perceived that the main cause of limited participation inside the home, outside the home, and during transportation was their wheelchair. The wheelchair is most likely the most important mobility technology, but it is also the device most associated with barriers. According to Post et al. (1997), there are significant complaints about wheelchairs among subjects with spinal cord injuries (SCI). Manual wheelchairs are often considered heavy and difficult to manoeuvre. The dimensions of the mobility device base will affect how the wheelchair can negotiate through tight spaces. Similarly, Mann et al. (1996) found that 26% of the problems associated with a wheelchair were related to the physical characteristics of the wheelchair (too heavy to push, too wide to use inside the home). In a real sense, a wheelchair is an extension of the user's body (Fogelberg, Atkins, Blanche, Carlson & Clark, 2009).

Therefore, it is critical that any wheelchair must match the user's current expectations, preferences, physical needs, and functional requirements based on his/her interactions with the environment - thus the client's psychosocial needs (Chaves et al., 2004).

Furthermore it has been indicated that social attitudes and self-concept is an obstacle to participation in the community and transportation use (Chaves et al., 2004). It is difficult to understand why these obstacles exist; however, Pierce (1998) found that the public lacks understanding of the life of people with disabilities and that the attitudes of others can have

an impact on activity performance. Therefore, consideration of the user's social attitudes and more importantly psychosocial needs are essential when wheelchairs are prescribed and provided.

#### **1.1.4 The provision of wheelchairs in South Africa**

Access to mobility devices in order to help persons with disability achieve their highest level of independence is supported by both national and international policy. The UN considers access to mobility devices as a basic human right (UN, 2006b). A right that is supported in several documents, policies and consort documents such as the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) (UN, 2006), The United Nations *Standard Rules for the Equalisation of Opportunities for Persons with Disabilities* (UN, 1998) and The World programme of Action Concerning Disabled Persons (UN, 1982). These UN policies reinforce that countries are responsible for ensuring that persons with disabilities living in those countries are able to achieve their highest level of independence. This includes taking effective measures to ensure availability and access to mobility aids, devices and assistive technologies (UN, 2006).

In South Africa, the right to an appropriate assistive device and especially wheelchairs has been outlined in policies such as the Integrated National Disability Strategy (INDS) (DoH, 1997) and the National Rehabilitation Policy (DoH, 2000a) since 1997. In 2003 the Department of Health adopted the WHO joint position paper (WHO, 2001) on the provision of mobility devices in less resourced settings and published a guideline document: South African National Department of Health Standardisation of Provision of Mobility Assistive Devices in South Africa (DoH, 2003). In 2007 the South African Government signed and ratified the UN Convention on the Rights of Persons with Disabilities and by ratifying it agreed that non-adherence to providing wheelchairs and other assistive devices to persons with mobility limitations can have legal implications.

All public health services in South Africa are managed by the National Department of Health. One of the services rendered by the National Department of Health to all state patients is the provision of assistive devices including wheelchairs (DoH, 2000a). These wheelchairs are ordered and procured off of a tender (South African National Treasury, 2010) (some provinces use a provincial tender while other provinces make use of the national tender). The Eastern Cape makes use of the national tender. Since 2000, a wide variety of wheelchairs

have become available on the South African national tender; including wheelchairs fit for urban, peri-urban and rural environments (DoH, 2000b).

All health professionals and even non-professionals who are involved in the field of wheelchairs and seating are offered a specialized seating course that was developed by the Provincial Government of the Western Cape Department of Health (PGWC DoH) and is available nationwide on request and depending on interest. The aim of these courses is to equip participants with the ability to prescribe and issue appropriate wheelchairs for their clients. These courses range from basic to advanced (PGWC DoH, 2009a; PGWC DoH, 2009b; PGWC, 2010). In addition to these courses the Special Interest in Seating (SPIN) group and the Wheelchair Advisory Sub Committee (WASC) offer regular refresher courses in wheelchair hardware and seating principles within the Western Region of the Eastern Cape.

Despite government's policy on prescribing and issuing wheelchairs prescription practice seems to vary between clinics within and between provinces in South Africa in terms of: who is allowed to prescribe wheelchairs; the knowledge of the prescriber; the types of wheelchairs prescribed; as well as the criteria used to guide prescription. In the Western Region of the EC where the basic seating course has been presented since 2008, a policy has been developed for the region stating that only occupational- and physiotherapists who have been trained in basic seating are allowed to prescribe, order and issue wheelchairs. However, in the eastern and central region of the EC no such policy exists and the concern remains that inappropriate wheelchairs are being ordered by any health professional, regardless of their training in seating. In the experience of the researcher and as confirmed by suppliers (Clare Hubbard, CE Mobility) in the EC<sup>1</sup> - a province that is classified as rural- the vast majority of wheelchair users are currently issued cruisers / standard folding frames (known as urban mobility aids), even though the necessary or possibly more appropriate aids are freely available on tender. The difference in price between the various devices is often a contributing factor to this, as therapists order the cheapest wheelchairs to 'stretch' the budget available for wheelchairs in the region. Irregular prescriptions are becoming more evident at follow-up seating clinics. The extent of the problem and reasons for this are widely speculated on, but has not been researched. Thus the current study evolved.

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<sup>1</sup> Clare Hubbard; CE Mobility representative Port Elizabeth

## **1.2 Study Problem**

The body of knowledge regarding the broader range of environmental context factors on successful wheelchair prescription and issuing is sparse. Until recently, assistive technology research and service delivery has focused primarily on technology-centred approaches. In South Africa wheelchair abandonment is high and despite guidelines, wheelchair seating workshops and training there seem to be discrepancies in the prescription and issuing process. A challenge also experienced in the Eastern Cape as mentioned above. It is unclear why this is so. In order to develop a better understanding regarding successful wheelchair outcomes, the literature recommends a more in-depth evaluation of the psychosocial impact the wheelchair has on the user. This knowledge may reduce the current gap in understanding relationships between the human -task-environment match (Lenker & Paquet, 2003) in order to optimise outcomes.

## **1.3 Motivation for the study**

It can no longer simply be assumed that assistive technology is beneficial without the necessary research to prove this (Persson et al., 1996; Smith, 1996; DeRuyter, 1998; Fuhrer, 2001; Audit Commission, 2003). Increased financial demand on health service has created a need for objective evidence to inform professional decisions and demonstrate the cost-effectiveness of assistive technology (Harris, Pinnington & Ward, 2005).

During an internal audit conducted by the researcher of the wheelchairs that had been issued at the Port Elizabeth Hospital Complex during the past two years, it was established that 96.65% of the wheelchairs that were currently being issued through this hospital complex (servicing three hospitals on a district level), were standard folding frames – known as an urban wheelchair. Many reasons could be speculated for this, but the findings validated the need for a closer look. Thus the researcher embarked on this study.

## **1.4 Significance of the study**

There is a need to describe wheelchair prescription practice in SA as well as describe the psychosocial needs of people in wheelchairs. By conducting this study, greater insight into whether or not wheelchairs are being appropriately prescribed in the Western Region of the Eastern Cape and whether or not these wheelchairs address the psychosocial needs of wheelchair users may be gained. Furthermore, a better understanding regarding the barriers



faced by prescribing therapists in this region may be able to assist rehabilitation managers and all those involved in seating in the Western Region of the EC in taking appropriate steps towards improving service delivery regarding wheelchair provision in this region.

### **1.5. Aims and Objectives**

The primary aims of the study were to describe current wheelchair prescription practice in the public sector of the Western Region of the Eastern Cape, and to determine whether the wheelchairs that are currently being issued address the psychosocial needs of persons with disability living in the Western Region of the Eastern Cape.

The specific objectives were to:

1. Describe characteristics of wheelchair users in the study setting.
2. Determine which wheelchairs were issued by therapists for persons with disabilities living in the study setting
3. Determine the patient's level of satisfaction with the wheelchair issued.
4. To determine how functional users are in wheelchairs issued in the study setting.
5. Determine the psychosocial impact of wheelchairs issued through the public healthcare system on persons with disabilities
6. To explore relationships between psychosocial needs and wheelchair specification.
7. Describe wheelchair prescription and wheelchair issuing practice as perceived by prescribing health professionals in the study setting.

To make recommendations to stakeholders based on the study findings

### **1.6 Outline of the study**

In chapter two, there will be an exploration of the current literature available regarding wheelchairs, seating, service delivery steps and psychosocial impact of wheelchairs. The methodology of the current study will be clearly outlined and motivated in chapter three. Thereafter the results will be given in chapter four and discussed in detail in chapter five. The last chapter, chapter six, will conclude the study's findings as well as discuss the shortcomings of the study and offer recommendations from study findings to stakeholders and for future research in this area.



# Chapter 2

## LITERATURE REVIEW

In order to adequately describe wheelchair prescription practice in the EC, a holistic overview of the specialised field of seating is imperative. An online literature search was conducted on the CINAHL, ScienceDirect, MEDLINE, Google Scholar and Cochrane databases using key terms and synonyms relating to assistive technology, mobility and disability; wheelchair and outcome measures. Appropriate Boolean operators were used to improve specificity. Hand searching of relevant texts, conference papers, cross-referencing, review of relevant websites and personal contact with those who specialize in the field of seating was also done to ensure most relevant literature and/or information was sourced.

This chapter discusses the different aspects that impact on wheelchair prescription practices, wheelchair abandonment and the psychosocial impact wheelchairs have on users. Additional research findings relevant to the current study, is also discussed.

### 2.1. Assistive Technology

Assistive Technology is described as any item, product system, or piece of equipment whether acquired commercially off the shelf, customized, or modified, that is used to maintain, increase, or improve functional capabilities of persons with disabilities [‘Technology-related assistance of individuals with disabilities act of 1988’ (PL 100 ± 407)]. Similarly a wheelchair is defined as a device providing wheeled mobility and seating support for a person with difficulty in walking or moving around (WHO, 2008). However, a wheelchair is only ‘appropriate’ when “it meets the user’s needs and environmental conditions; provides proper fit and postural support; is safe and durable; is available in the country and can be obtained and maintained and services sustained in the country at an affordable cost” (WHO, 2008: 9).

The rapid change in the healthcare system and the development of emerging assistive technology dictates that clinicians and rehabilitation scientists keep pace. The field of assistive technology and particularly the subspecialty of seating and wheeled mobility have not yet developed a mature scientific body of evidence. To date, remarkably little research has been done on the link between assistive technology interventions and the everyday

functioning and health of wheelchair users (Sprigle, Cohan & Davis, 2007). All involved in the seating industry should be interested in learning about whether new treatments and technologies are effective in impacting a person's everyday life (Sprigle, Cohan & Davis, 2007).

It is estimated that at least 20 million people with disabilities (PWDs) in developing countries worldwide need wheeled mobility devices. Unfortunately, very few of these individuals have the wheelchairs they need, while others have wheelchairs that are inappropriate for their environments and lifestyles (McAdam & Castelyn, 2005).

## **2.2. Policies on Wheelchair Provision and Seating**

There are several national and international policies regarding wheelchair provision as well as wheelchair seating. A comprehensive wheelchair service is outlined in eight service steps in the WHO guidelines (WHO, 2008). The WHO guidelines also include minimum standards for each step (WHO, 2008; Greer et al., 2012). These service steps are:

1. Referral and Appointment; This step refers to the process where when a user is referred for a wheelchair, an immediate appointment is made or the user is put on a waiting list – depending on priority. Users with a terminal illness or other life threatening complications such as pressure sores should be prioritised (WHO, 2008).
2. Assessment; This should be done by trained personnel and the necessary assessment equipment should be readily available, such as a plinth, measuring tape and foot blocks. All assessments need to be adequately documented. Most importantly, if the user's needs exceed the assessor's skills, the user needs to be referred to an institution with personnel who have the adequate skills, an outreach to the user by a skilled assessor needs to be organised or the unmet needs have to be clearly documented and attended to as soon as possible (WHO, 2008).
3. Prescription; During this step users should ideally be given the opportunity to try out different types of wheelchairs and be involved in choosing the wheelchair. The prescription should detail: the type and size of the wheelchair, additional components needed including customised components and the information that the user needs to have before leaving the prescribing institution. An estimate of when the wheelchair will be ready should be given to the user (WHO, 2008).

4. Funding and Ordering; Good practice in ordering includes having available stock of wheelchairs and additional equipment to minimise waiting times. A system should be in place keeping track of pending orders from suppliers as well as giving feedback about quality issues to suppliers (WHO, 2008).
5. Product Preparation; During this step the wheelchair is labelled with the user's name and a serial number. Modifications to the wheelchair and installation of customised seating systems or postural support equipment should only be done by adequately trained personnel. Equipment needs to be checked for safety and quality before delivery to the user (WHO, 2008).
6. Fitting; Once again this should only be done by trained personnel and where possible by the same staff who did the prescription. The fit is assessed both stationary and while the user propels until an appropriate fit is achieved. If the wheelchair fit is not acceptable adjustments are made, or in some cases additional equipment or a re-assessment is necessary. Ideally a user should not be issued with the wheelchair if the fit is not acceptable (WHO, 2008).
7. User Training; A user – training checklist is completed with the user and ticked off as the user is trained in each area that they need. Peer- training by other wheelchair users is advised and beneficial (WHO, 2008).
8. Follow –up, Maintenance and Repair; Follow- up appointments should ideally include clinical, technical and training personnel. Frequency of follow-up appointments depend on the needs of the user and priority is given to: children (due to frequent change in physical build and growth spurts), users who are at risk for developing complications such as pressure sores, users with customised postural support equipment that needs frequent checking and users who had difficulty with their initial training and needs more intense training (WHO, 2008).

The two most important national policies as they relate to this study is the South African National Rehabilitation Policy (NRP) (DoH, 2000) and the South African National Guidelines on the Provision of Assistive Devices policy (SA National Guidelines). The SA National Guidelines outlines requirements and responsibilities regarding the provision of assistive devices in the public sector of South Africa (DoH, 2003). Specific protocols regarding the key service steps in the provision of assistive devices and wheelchairs are included in the SA National Guidelines.

The SA National Guidelines (DoH, 2003) include most of these service delivery steps form the WHO guidelines as presented above, but not all of them and also lack some of the specifications that are included in the WHO Guidelines (WHO, 2008). Three important service delivery steps are not included in the SA National Guidelines (DoH, 2003). These three steps are:

1. Referral and Appointment
2. Product Preparation
3. Follow- up

The term: “issue/ issuing of wheelchairs” will henceforth be used when referring to a combination of these six steps. An aspect that plays an important role in the issuing of wheelchairs is the design of the wheelchair.

### **2.3. Wheelchair Design**

There are different general wheelchair designs available and each design is specific to provide a certain function or purpose. For the purpose of this review, wheelchair design will be discussed specifically looking at four wheeler and three wheeler wheelchair designs. A four wheeler wheelchair can either be foldable or rigid. Generally, a foldable four wheel wheelchair design (such as the CE Cruiser) is suitable for low active clients and is specifically designed for indoor/ urban use. These designs are less effective on uneven terrain as it needs four points of contact for traction and stability. This is why four wheel wheelchairs often get stuck on uneven terrain when one rear wheel loses contact and traction (WCPG DoH, 2009a; WCPG DoH, 2009b; WCPG DoH, 2010). In contrary, three wheeler designs (like the ATW) are specifically designed for rough terrain and will at any time have all three wheels on the ground for optimal propulsion and traction. To use a 3- wheel design wheelchair inside small spaces is impractical, as these types of wheelchairs have both a long wheelbase and a large turn- circle (WCPG DoH, 2009a; WCPG DoH, 2009b; WCPG DoH, 2010).

Function within a wheelchair can be affected by many wheelchair design features including: Overall length, type and size of the wheelchair, seat height, arm- and footrests, weight of the wheelchair, transportability, access to the rear wheel (how easily the user can reach the rear wheels with their arms to propel), rear wheel camber and stability versus mobility setting (centre of mass). Length and type of wheelchair (i.e. rural 3- wheel design with longer

wheelbase) are especially important when considering the function of the user indoors; as this has a direct effect on access to household items such as cupboards and functional activities such as transfers. The four wheel foldable type wheelchair has a relatively high seat and this can also affect function as a seat that is too high restricts access under tables/ desks and can affect stability (related to centre of mass (COM)). The size of the wheelchair will affect the user's fit and therefore postural support as well, as this prevents the pelvis from shifting laterally or moving into an obliquity. The size will also affect the user's access to the rear wheels for propulsion as well as access to small indoor environments. Thus, the appropriate size may further facilitate function (WCPG DoH, 2009a; WCPG DoH, 2009b; WCPG DoH, 2010).

Correct set-up of the wheelchair and unloading of the front castors (ensuring that the COM of the user is over the rear wheels) will improve the ability of the user to clear the front castors (i.e. on rural terrain, curbs) and thus enhance both manoeuvrability and safety. Due to the design of the four wheel foldable wheelchair (loaded front castors) it is exceptionally difficult to wheelie up a curb, as the weight of the user is often loaded onto the front castors with no setting to unload these castors. Wheelchairs with long wheelbases such as the three wheel wheelchair design thus compensate for users who lack advanced wheelchair skills in that it ensures that the users weight is over the rear wheels and makes clearing obstacles with the front castors a lot easier. These wheelchairs are recommended for active, independent users who predominantly propel on uneven, rural/ semi- rural terrain (WCPG DoH, 2009a; WCPG DoH 2009b; WCPG DoH, 2010).

Currently, both four wheel and three wheel wheelchair designs are available on South African national tender and thus available to the participants of the current study (South African National Treasury, 2010).

## **2.4. Specialized seating**

The diversity of wheelchair users, and the different contexts in which occupations are performed, emphasizes the need for different designs of wheelchairs and no single wheelchair can meet the needs of all wheelchair users. As such special or customised seating is recommended (Mukherjee & Samanta, 2005). Special seating refers to any necessary insert or adaptation, including the seat base and back, which is placed in a wheelchair frame specially designed or modified for the individual. Special seating not only reduces secondary

complications (Mann, Hurren & Chavat, 1996; Zollars, 1991), but has also been shown to contribute to better functioning (Scherer & Cushman, 2001; Smith, 1996; Chaves et al., 2004).

Seating technology in the developing world however is not always available. There is an overwhelming demand for seating that is not being fulfilled and attempts to address backlogs, especially in under- resourced settings, have often resulted in *en mass* issuing of charity wheelchairs – typically one design, one size fits all wheelchairs (McAdam & Castelyn, 2005; Mukherjee & Samanta, 2005).

Outcomes of assistive technology use are important indicators of a quality service delivery process (DeRuyter, 1997; Fuhrer, 2001; Jutai et al., 1996; Wielandt & Strong, 2000; Scherer, 1996). From the perspective of consumers and rehabilitation providers, equally or more important is being able to create an optimal match between person and technology at the outset and involve the consumer in assistive technology selection (Day et al., 2002; Scherer, 2002; Scherer, 2005). Recent developments in outcomes assessment research confirm the importance of an appropriate early assessment of consumer needs for assistive technology (Lenker & Paquet, 2003; Lenker & Paquet, 2004; Fuhrer et al., 2003; Scherer et al., 2004). As the available options and features of assistive technology have increased, their use has been more widely considered and recommended (Cook & Hussey, 2002). Differences among individual users can be better accommodated due to this expanded choice; however, the process of matching person and technology remains complex because people's expectations of and reactions to technologies are complex (Scherer, 2005).

Those assisting in the selection of a wheelchair for an individual require an understanding of the needs and context of the user, as well as the rationale behind different wheelchair designs. It is, therefore, important that assistive devices are viewed as being both impairment-specific and person-specific - an approach which is supported by our Department of Health (DoH, 2000).

A critical review of research literature of seating interventions by Reid (2002) supports the current researchers assumption that there is enough emphasis on constructs at the impairment level but that there is inadequate attention given to functional and psychosocial issues when prescribing a wheelchair. The results reported in twelve of the sixteen studies included in the review were for the most part from the perspective of the researchers who planned and

carried out the investigations. Only three studies presented results from the perspective of wheelchair users themselves and/or caregivers of users. The perspectives of teachers and parents were presented in one study. If the wheelchair user's perspective is not taken into account, abandonment is more likely to happen (Scherer et al., 2005).

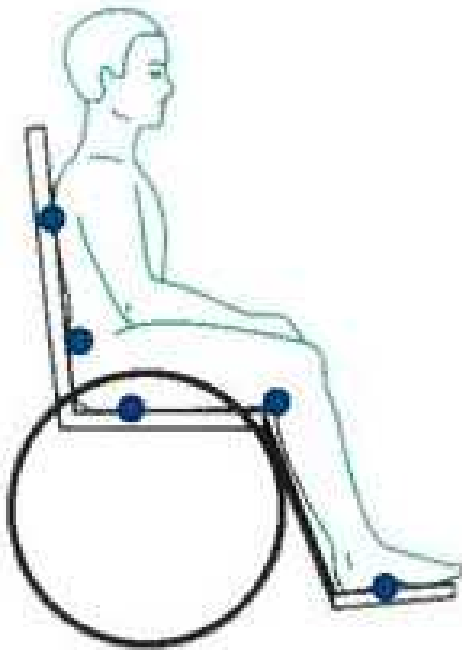
## **2.5. Seating Posture in a Wheelchair**

It is not uncommon for posture to be evaluated as an outcome of wheelchair use (Hobson & Tooms, 1992; Minkel, 2000). A direct correlation between poor sitting posture and low back pain exists (Haarms, 1990; Samuelsson, Larsson, Thyberg & Tropp, 1996). Similarly it has been shown that poor sitting posture is related to a reduction in functional ability (Bolin, Bodin & Kreuter, 2000).

Neutral sitting posture (Figure 1) has been described as the ideal sitting posture for an individual in a wheelchair, since it can assist to preserve joint range of motion (ROM), maintain muscle lengths, prevent pain and discomfort, maintain normal muscle tone and provide optimal biomechanical alignment which in turn will affect the efficacy of movement (Black, McClure & Pelansky, 1996).

The latter three articles describe neutral sitting posture as observed from the front (anterior view) as: head upright, aligned over the pelvis and trunk and in the midline of the body; shoulders relaxed with the arms free for functional activities; pelvis and shoulders horizontal; right and left sides of the trunk symmetrical; and no rotation (Black, McClure & Pelansky, 1996). The neutral sitting posture as seen from the lateral view is described as: neutral alignment displaying a double "S" curve of the spine, the lumbar and cervical spines showing an anterior curve and the sacral and thoracic spines showing a posterior curve. The lateral alignment in sitting is slightly flattened. If a plumb line were to be used, it would run vertically through the ear, shoulder and hip joints and also through the anterior vertebral bodies of the lumbar and cervical curves. The pelvis is balanced upright on the ischia and either in slight anterior tilt or in neutral. The anterior superior iliac spine (ASIS) and the posterior superior iliac spine (PSIS) are at the same height or the PSIS is slightly higher than the ASIS. Anatomically in this alignment the spinal facet joints are in their most stable position, making maximum joint surface contact with each other (closed pack position). This ensures that there is no adverse stretch placed on the spinal ligaments, muscles or capsules. Hips should be flexed at 90° with the femurs either parallel to each other or minimally

abducted (maximum 5-8°). When seated in a four wheel folding frame design wheelchair knees are generally flexed at 90° with the ankles in a neutral position while the feet are resting on a flat supporting surface. In a more active wheelchair and often in sports wheelchair designs, the feet are tucked in underneath the user resulting in more than 90 degrees flexion at the knees (PGWC DoH, 2009a).



**Figure 2-1: Optimal wheelchair seating (www.phc-online.com)**

## **2.6. Impact of environment on the outcomes of seating**

The environmental influence on seating was established as a research priority at the ‘State of the Science Conference’ in Georgia in 2007. At this conference it was decided that despite the Americans with Disabilities Act and advances in wheelchair technology to overcome physical barriers, the environment continues to present hurdles, whether real or perceived, to the activity and participation of wheelchair users (Sprigle, Cohen & Davis, 2007).

Although it is widely accepted that the consumer’s home environment should be the primary setting in which to evaluate the effectiveness of wheelchair mobility, dexterity and overall function of consumers, very few studies have used this context (Reid, 2002). According to a critical review by Reid (2002), up to 2002, the majority of studies (n = 11 to 16) into adult



wheelchair mobility and seating were undertaken in a clinic or laboratory setting and only four studies were conducted in the home environment. Two of these studies were conducted via telephone interviews and/or a questionnaire and only one study was conducted in the work place in an office setting. Another study was conducted in the community but did not specify which community settings. As seating and wheelchair technology continues to progress at a rapid rate, literature and research in this area is abundant except when referring to the developing world. Although awareness of the need for seating technology in underdeveloped countries continues to expand, the lack of evidence specifically relating to service delivery within these countries is still evident (Borg, Lindstrom & Larsson, 2009).

Persons with disabilities using wheelchairs in rural settings face many barriers that those in urban environments often don't face, such as uneven terrain (including gravel, grass, mud and sand) as well as access to healthcare facilities as they often live far from these centres (PGWC DoH, 2009a). The appropriate wheelchair can ease mobility over uneven terrain (PGWC DoH, 2009b) and thereby assist the person in accessing healthcare and other community facilities.

It is believed that as the person–environment–device match tightens, the quality of service delivery and consumer satisfaction will be heightened, the abandonment or disuse of assistive technology will be reduced, costs will be contained, and the consumer's functional abilities and quality of life will be improved (Martin et al., 2011).

## **2.7. Problems associated with sitting in a poor postural alignment**

The most common secondary impairments associated with prolonged poor postural alignment in sitting include pain and discomfort; a change in muscle tone (increase or decrease in case of spasticity in persons with upper motor neuron lesions), loss of range of movement (ROM), muscle weakness and a decrease in endurance or fitness (PGWC DoH, 2009a).

These impairments can lead to poor postural alignment which negatively impacts range and control of movement for example the development of scoliosis or other postural deformities. The slumped posture may affect safety of swallowing and limit communication. Other functional limitations include reduction in the efficacy of propulsion in a manual wheelchair, reduction in balance and therefore difficulty in transfers to and from the wheelchair, difficulty

in self-care tasks such as dressing due to reduced stability and balance within the wheelchair (PGWC DoH, 2009a; Engström, 2002).

These functional limitations lead to participation restrictions such as getting to work (transfers to the car/ taxi), functioning at work (balance impacting on UL function), social interaction and communication in the community and moving around in the community (decrease in propulsion efficacy) (PGWC DoH, 2009a; Engström, 2002).

### **2.7.1 Physical Problems**

The following physical problems are reported in the literature:

- Discomfort and pain. In one Canadian study, sitting comfort was rated by wheelchair users as the most important factor affecting their satisfaction with their seating aid (Weiss-Lambrou, Tremblay, LeBlanc, Lacoste & Dansereau, 1999).
- Increased muscle tone in the upper limbs can occur when the trunk is kept in a flexed position, causing abduction of the scapula's and subsequently internal rotation and adduction of the shoulder joints. Because these form part of the components commonly seen in the mass flexor pattern it will therefore encourage flexor spasticity in the upper limbs. This can often be aggravated by the fact that the elbow, wrist and fingers are also kept in a flexed position on the user's lap (PGWC DoH, 2009a; Engström, 2002).
- Muscle tone may similarly increase in the lower limbs. Lower trunk flexion and posterior pelvic tilt result in relative extension at the hips, which may encourage the extensor spastic pattern of the lower limbs. This problem is often aggravated by adduction and internal rotation deviations of the lower limbs (PGWC DoH, 2009a; Engström, 2002).
- Poor proximal biomechanical alignment will result from poor postural alignment and this in turn affects the efficacy of movement (PGWC DoH, 2009a; Engström, 2002).
- Sitting with a slumped posture with poor support results in a flexed lumbar spine, and in time range of movement is lost (PGWC DoH, 2009a; Engström, 2002).
- Poor alignment of the lumbar spine results in poor alignment of the thoracic and cervical spine, and poor orientation of the head in space. In users with weakness, poor endurance and other neuro-muscular control problems, control of the position of the head in space will be difficult. This will affect the safety and efficacy of feeding, swallowing and speech (PGWC DoH, 2009a; Engström, 2002).

- Sitting in a slumped posture will limit lung volume and negatively impact on respiratory capacity (PGWC DoH, 2009a; Engström, 2002).
- A poor posture can result in compression of internal organs – this may cause difficulty in food digestion as well as bowel and bladder problems (PGWC DoH, 2009a; Engström, 2002).
- Poor sitting posture and its negative impact on function, enhance the image of disability and affects the user's self-worth and self-esteem (PGWC DoH, 2009a; Engström, 2002).
- Slumped sitting causes the pelvis to roll backwards which adds pressure to the sacrum (a high risk pressure area), and this can contribute to the development of pressure sores (PGWC DoH, 2009a; Engström, 2002).

### **2.7.2 Functional Problems**

The following are functional problems reported in the literature:

- The decrease in lumbar spine range of movement will limit pelvic mobility towards neutral and therefore the following functions can be influenced negatively:
  - The ability to stand up from sitting as both lumbar extension and anterior pelvic tilt are necessary to stand up.
  - The ability to transfer.
  - Functional forward reach with the upper limb, as true gleno-humeral flexion is restricted to 120° (PGWC DoH, 2009a; Engström, 2002).
- Communication and social interaction can be negatively affected due to the poor head control and inability to orientate the head in space in a continuous slumped sitting posture (Hlicks, Fritz, Delitto & Mishock, 2003; Li, McClure & Pratt, 1996; Langton, 2000).

### **2.7.3 Long term problems**

The above impairments and functional limitations may lead to secondary complications such as:

- Contractures of muscle and soft tissues: In the upper limbs and trunk the Pectoralis muscle group as well as the internal rotators of the shoulder are most at risk due to the prolonged forward flexion and internal rotation position used for forward propulsion when seated incorrectly. In the lower limbs the Hamstrings, adductors, abductors, Tendon

Achilles, Iliopsoas and Gluteus Maximus are particularly at risk due to the hip and knee flexion positioning that accompanies seating (PGWC DoH, 2009a; Engström, 2002).

- Postural deformities (asymmetry / kypho-scoliosis) can develop due the persistent poor posture. Facet joints lose stability when they are not in the closed-pack position, the joint surfaces slide apart, thereby making less surface contact with each other. Muscles, ligaments, capsules and other structures are stretched and the stability of the spine is compromised (O'Sullivan et al., 2006a; Scannel & McGill, 2003).

## **2.8. Impact of varying prescription practices**

In 2007, a study was published by Sprigle, Cohen & Davis wherein research priorities in the scope of seating and wheeled mobility were collected and reported. At the 'State of the Science Conference' held by the Georgia Institute of Technology (Mobility Rehabilitation Engineering Research Center) to address challenges in studying the health, activity and participation of wheelchair users five research priorities were identified. One of the priorities identified stated that a proper and thorough seating and mobility evaluation is necessary to insure the health and function of a client. As with the provision of any service, the quality of a wheelchair evaluation outcome is related to the skill of the provider(s). The recommendation was therefore to include assessment of user needs and training of the user on the recommended use of the equipment (Sprigle, Cohen & Davis, 2007).

In a another study that aimed to describe the process of establishing an evaluation of wheelchair prescription practices by occupational therapists in a spinal injury rehabilitation unit in South Australia; Di Marco, Russel & Masters (2003) listed some of the factors and possible reasons for unsuccessful wheelchair prescription outcomes as follows:

- The lack of involvement of the user in the prescription process (Phillip & Nicosia, 1990; Phillip & Zhao, 1993; Scherer, 1996);
- Poor prescription practice as well as lack of training of professionals (Cooper et al., 1996; Phillips & Nicosia, 1990; Smith et al., 1995);
- A change in the needs of the user from the time of prescription (Cushman & Scherer, 1996; Phillips & Zhao, 1993; Scherer, 1996);
- Poor device performance (Phillips & Zhao, 1993; Post et al., 1997; Scherer & Vitaliti, 1997); and
- Unsatisfactory design features and poor fit (Post et al., 1997; Scherer & Vitaliti, 1997)

The authors (2003) also stated that many of these factors that are thought to contribute to poor outcomes in wheelchair prescriptions may be influenced positively if they are addressed and monitored at the time of service delivery.

Through a process of defining the objectives of wheelchair prescription with the implementation of focus groups amongst the prescribing therapists, the goals of wheelchair prescription were defined as “the wheelchair provided will be safe and comfortable, maximise independence, meet postural requirements and have reasonable durability” (Di Marco et al., 2003: 33). This definition supports the argument that wheelchair prescriptions need to be specific and focused on each and every individual to optimise independence, maintain posture and/ or prevent deformities.

Although the importance of regular periodic follow up has been described by many in the field of assistive technology (Garber & Krouskop, 1997; Kohn et al., 1991) and wheelchairs (WHO, 2008; Fogelberg et al., 2009; Hansen, Tresse & Gunnarson, 2004), it does not seem to be standard practice. Periodic follow up allows for consideration of factors leading to poor outcomes such as: (i) the needs of the wheelchair user changing; (ii) poor device performance; and (iii) unsatisfactory design features and poor fit. This allows management of these factors before they lead to dissatisfaction and, ultimately, abandonment (Di Marco et al., 2003). Thus, although it has been identified as a contributing factor, regular follow- ups are currently not being done as often or as in- depth as needed. Whether this is due to lack of patient and prescribing health professional education on the importance of follow- ups, or poor patient compliance, remains to be established.

## **2.9. Psychosocial impact of assistive devices**

One aspect that is seldom reported in the literature is the psychosocial challenges faced by individuals following a disabling event resulting in the need for an assistive device such as a wheelchair (Scherer & Cushman, 2001). Investigating the psychosocial impact of an assistive device on its user may shed some light into the reasons for its use and abandonment and possibly contribute to improved design of devices and related services (Day & Jutai, 1996). Quality of Life (QoL) impact as defined by Renwick, Brown & Raphael (1994), is the effect of the device on, “the degree to which a person enjoys the important possibilities of his/her life”. For wheelchair users, this reality can be empowering or devastating. A wheelchair has an impact on the user’s QoL, be it positive or negative, as a wheelchair that truly matches the

user's environment, level of function and physical build will enable such a person to enjoy the important possibilities of his/ her life (Cushman & Scherer, 1996).

Quality of life can be perceived and understood in various ways, as different professions define this concept based on their own philosophy. The medical view relates QoL to life expectancy and optimal life quality, focussing only on the health aspect. In rehabilitation, the concept of QoL is defined in terms of maximising function and independence for the individual (Cook & Hussey, 2002). An assistive device should promote good quality of life for the user to the extent to which it makes the user "feel competent, confident, and inclined (or motivated) to exploit life's possibilities" (Day & Jutai, 1996).

These needs should be taken into account when prescribing a wheelchair for the user (Putzke et al., 2002; Leduc & Lepage, 2002). In Post et al's study of satisfaction and availability of services for people with spinal cord injury, 35.9% of participants had complaints about their manual wheelchairs. The different type of wheelchairs was criticized on the basis that they were too heavy, too vulnerable i.e. felt as though the wheelchair was fragile and not durable, difficult to manoeuvre, or that they were not aesthetically acceptable. Studies into outcomes of wheelchair prescription report wheelchair user dissatisfaction with: wheelchair manoeuvrability (Post, van Asbeck, van Dijk & Schrijvers, 1997; Bell & Hinojosa, 1995) wheelchair design (Hesse, Gahein-Sama & Mauritz, 1996; Scherer, 1996) weight and rolling resistance (Post, van Asbeck, van Dijk & Schrijvers, 1997; Hesse, Gahein-Sama & Mauritz, 1996) limitations placed on function, mobility and access (Bates, Spencer, Young & Rintala, 1993; CunniVe, 1984) ; physical discomfort (Bell & Hinojosa, 1995; Samuelsson, Larsson, Thyberg & Tropp, 1996; Harms, 1990; Curtis, Drysdale, Lanza, Kolber, Vitolo & West, 1999; CunniVe, 1984) difficulties transporting the wheelchair (Hesse, Gahein-Sama & Mauritz, 1996) – all of which has a direct impact on the user's QoL (Kittel, Di Marco & Stewart, 2002).

## **2.10. Abandonment or non-use of assistive technology**

Despite the fact that the motivation for issuing a wheelchair is to improve functional ability, the high incidence of reported abandoning of wheelchairs (Phillips and Zhao, 1993; Scherer & Cushman, 2001; Mukherjee & Samanta, 2005) is of major concern especially given that wheelchairs are expensive assistive devices. These authors reported that most abandonment of assistive technology occurs after five years or within the first year of use. Abandonment of

any assistive device is a waste of a resource in an environment where there is an increased need for accountability and cost containment in the provision of assistive technology. If the wheelchair had also been measured and specifications added for the user, abandonment now even suggests the loss of an opportunity to enhance an individual's quality of life (Parker & Thorslund, 1991).

The five goals of wheelchair prescription as defined by Brittel (1990) are to maximize the client's independent mobility; prevent / minimize deformity or injury; maximize independent functioning; project a healthy, vital, attractive 'body image'; and minimize short- and long-term costs.

The early abandonment of a customized wheelchair suggests a failure in the achievement of one or more of these goals and is indicative of a failure to meet the needs of the wheelchair user and of society as a whole (Di Marco et al., 2002). The most common reason for wheelchair abandonment is the physical environment. Lack of adaptability to the environment or habitat, frequent damage and unable to propel are most commonly cited as environmental barriers to optimal wheelchair use (Mukherjee & Samanta, 2005).

On average one third of all assistive technology devices are abandoned by users (Scherer & Cushman, 2001). In India, the high number of abandoned wheelchairs was described by Mukherjee & Samanta in 2005, which during their study found that of 162 recipients of charity wheelchairs, only 29 were still using their wheelchairs and only 7.4% were regular users with 10.49% described as occasional users. They went on to establish the cause of rejection and found that the highest percentage (33.92%) of abandonment was due to habitat adaptability. The 112 recipients of wheelchairs, who had in fact abandoned their wheelchairs, were questioned regarding the cause of their rejection of the wheelchair, 28.57% reported that pain, fatigue and discomfort had led them to rejecting the device, 11.6% reported that UL involvement meant that they could not use the wheelchair and therefore discarded it, 15.7% complained about the frequent damage to the wheelchair's due to the harsh terrain, causing them to abandon their wheelchair's and 10.71% were 'unable to drive' the wheelchair and therefore abandoned it. By far the biggest contributing factor for the recipients was the inability to adapt to the environment, which caused 33.92% of the wheelchair users to abandon their charity wheelchairs. They concluded: "An improper fitting wheelchair is liable to be discarded, as it does not provide comfort, safety, stability or optimal functionality" (Mukherjee & Samanta, 2005: 593).



In SA similar findings are reported by McAdam & Castelyn (2005) who investigated the effectiveness of the 1997 wheelchair project in Mpumalanga (one of the nine provinces of South Africa) an *en masse* issuing of standard folding frame wheelchairs. A four year retrospective survey was conducted in which recipients of the 1997 wheelchair project were followed up (McAdam & Castelyn, 2005). The authors concluded that the design of the wheelchair has an impact on the degree of mobility independence attained by the client, and that one wheelchair fits all created problems for the users and may have been less cost-effective for the service provider than issuing wheelchairs which are designed according to the clients' individual needs.

The authors also reported that poor access to repair services and inadequate wheelchair repair, maintenance and dexterity skills accounted for the reduced usage of their issued standard wheelchair. Reasons for total abandonment of their wheelchair reported by participants in this same survey included: inaccessibility of environment, lack of dexterity skills and lack of motivation to gain independence (McAdam & Castelyn, 2005).

Some studies have reported abandonment rates for mobility aids as high as 34% at three months following issue (Phillips & Zhao, 1993) and 36% at 12 months following issue (Cushman & Scherer, 1996). Further studies into outcomes of wheelchair prescription also report on wheelchair user dissatisfaction with: wheelchair manoeuvrability (Post et al., 1997; Bell & Hinojosa, 1995), too high weight and rolling resistance (Hesse, Gahein-Sama & Mauritz, 1996); inappropriate wheelchair design (Scherer, 1996); limitations placed on function, mobility and access (Bates, Spencer, Young & Rintala, 1993; CunniVe, 1984); physical discomfort (Weiss-Lambrou, Tremblay, LeBlanc, Lacoste & Dansereau, 1999), and difficulties transporting the wheelchair (Hesse, Gahein- Sama & Mauritz, 1996). Other reasons for poor outcomes include: a change in the needs and priorities of the user; a lack of consideration of the opinion of the user in the process; poor device performance; easy device procurement; poor prescription practices; and a lack of experience in assistive technology use (Di Marco et al., 2002).

A qualitative study was done by Kittel, Di Marco & Stewart (2002) to assess factors influencing manual wheelchair abandonment for three individuals with spinal cord injuries. The results were consistent with findings from the literature concerning dissatisfaction and abandonment of assistive technology. For these three individuals the lack of experience in wheelchair use and selection, the functional limitations encountered with the design of the



wheelchair and the manner and timing of the prescription process combined to lead to dissatisfaction and ultimately abandonment. The authors (2002) further stated that as the person–environment–device match tightens the quality of service delivery and consumer satisfaction will be heightened, the abandonment or disuse of assistive technology will be reduced, costs will be contained, and the consumer's functional abilities and quality of life will be improved.

Another variable presumed to affect wheelchair use is the time to possession of the wheelchair. Phillips and Zhao (1993) researched the predictors of assistive technology abandonment in 227 adults with a variety of disabilities. Roughly one third (29.3%) of all the participants had abandoned their assistive devices. Another important part of wheelchair prescription is the service delivery including follow-up service. If devices are checked regularly, errors can be corrected and the use and or non-use can be monitored properly and continued usage insured (Welsch & Flynn, 1997).

## **2.11. Outcome Measures**

There are unique challenges that accompany research design in the area of wheeled mobility and seating. The scarcity of reliable outcome measure, length of time needed for the service delivery component (evaluation, time between evaluation and procurement and waiting time before follow-up) as well as other possible confounding factors specific to the environment, technology and the person, increase the complexity related to this type of research (Sprigle, Cohen & Davis, 2007). Variants include but are not limited to differences in severity of illness, patient co-morbidities; system level variables, such as policies and regulations influencing patient care practices and funding; skills and training, clinician knowledge; and variations between technologies and environment. Challenges in designing methodologies and or outcome measures that can control for these confounding variables are vast. For these reasons, scientists are often reluctant to study the effectiveness of assistive technology interventions related to everyday function (Sprigle et al., 2007).

The development and use of outcome measures for mobility assistive technology is a relatively new and evolving field (Gelderblom & de Witte, 2002). Many rehabilitation outcome measures focus on motor development, function and ambulation (Dittmar & Gresham, 1997). However, measures that assess the 'normality' of function can fail to capture the degree of autonomous participation achieved with technology (Benedict et al.,

1999; Gelderblom & de Witte, 2002). To stimulate the development of device-specific outcome measures, Fuhrer et al (2003) incorporated the differing priorities and needs of stakeholders involved in assistive technology delivery and use into an assistive technology outcome measure framework. Similarly, Lenker & Paquet (2004) proposed a holistic, person-centred model to predict assistive technology usage. In this model, the use of assistive technology is determined by the motivation and needs of users as they consider opportunities to use assistive technology, perceived benefits and alternative solutions. The aim of the review by Harris, Pinnington & Ward (2005) was to assess the adequacy of available outcome measures to evaluate the impact of mobility assistive technology on participation. None of the outcome measures assessed were specifically developed to measure participation - a key factor of the International Classification of Functioning (ICF), although mobility for participation is a priority for most users (Harris, Pinnington & Ward, 2005) and a concept recently identified by the World Health Organisation (2002). Therefore, it is imperative that mobility assistive technology is evaluated from this perspective using psychometrically robust measures to ensure that reliable and valid evidence is used to inform practice (Streiner, 2003; Lenker et al., 2004). It is suggested that there is a need to develop an outcome measure for people with motor impairments, following the model proposed by Lenker and Paquet (2004), to ensure that the needs and perceptions of the user are at the centre of provision and evaluation. Some of the measures reviewed recorded user perceptions, but what was lacking was a profile of common mobility-related participatory tasks. This could help therapists who prescribe equipment or develop ambulatory and functional skills to learn which equipment works best and under what circumstances (Harris, Pinnington & Ward, 2005). It could also provide a means of evaluating new technology because none of the measures generated the information required to understand how specific characteristics of mobility assistive technology have an impact on participation (Smith, 1996; DeRuyter, 1997; Gelderblom & de Witte, 2002). They concluded that the reliability and validity of many of the outcome measures assessed was demonstrated, but the most conspicuous deficiency is in the assessment of social participation in relation to mobility achieved through the use of mobility assistive technology. They suggested that further research is required in order to develop an outcome measure for this purpose. Such a measure could help to improve the cost-effectiveness of services (DeRuyter, 1998), while raising awareness of the impact that effective mobility assistive technology can have on 'Improving the life chances of disabled people' (Department of Work and Pensions et al., 2005). Outcome measures do however exist which also takes into consideration the impact on care givers- which is of great

importance when users who cannot transfer or propel themselves independently are assessed (Day & Jutai, 1996).

Amongst the outcome measures assessed in their review, the Psychosocial Impact of Assistive Devices Scale (PIADS) and the Functioning Everyday with a Wheelchair (FEW) were discussed. The aim of the PIADS was described as to assess effects of assistive technology devices on psychosocial aspects of quality of life, while the aim of the FEW was described as to evaluate functional changes associated with seating-mobility interventions. Both were established to be adequate assessing what it was intended to. The outcome measures reviewed evaluate mobility assistive technology from different perspectives to meet the needs of the various stakeholders (Fuhrer et al., 2003). Furthermore, the PIADS was established to be an adequate outcome measure when assessing the impact of assistive technology on caregivers.

The ultimate goal of practitioners is to provide clients with technology that improves quality of life and matches their and their caregivers' capabilities. It is thus essential to consider a holistic view that includes the consumer, the proposed technology and the environment where the consumer will utilise the assistive device. For this reason the FEW was designed to quantify consumer function related to seating and wheelchair mobility interventions. It was designed with the expectation to benefit users by ascertaining the level of functional change as a result of receiving the most appropriate technology. Additionally, it is also intended to enable practitioners to provide documentation and justification of the efficacy of seating and wheeled mobility interventions (Mills et al., 2002).

## **2.12. Conclusion derived from the literature review**

From the literature review it is also evident that wheelchair prescription has evolved tremendously and it is recommended that these be custom fitted to its user. Although policies exist within South Africa regarding wheelchair prescription, three important service delivery steps as described by WHO (2008) have been left out i.e. Referral and Appointment; Product Preparation and Follow-up. The current study aims to describe wheelchair prescription practice in the EC and describe the psychosocial impact on the user.

# *Chapter 3*

## **METHODOLOGY**

This chapter describes the methods used in the current study which aimed to describe wheelchair prescription practice in the Western Region of the Eastern Cape (EC) as well as determine client satisfaction related to their prescribed wheelchair.

### **3.1. Research Question**

What is the wheelchair prescription practice in the public sector in the Western Region of the Eastern Cape; and do the prescribed wheelchairs address the psychosocial needs of wheelchair users?

### **3.2. Aims and Objectives**

The primary aims of the study were to describe current wheelchair prescription practice in the public sector of the Western Region of the Eastern Cape, and to determine whether the wheelchairs that are currently being issued address the psychosocial needs of persons with disability living in the Western Region of the Eastern Cape.

The specific objectives were to:

1. Describe characteristics of wheelchair users in the study setting.
2. Determine which wheelchairs were issued by therapists for persons with disabilities living in the study setting
3. Determine the patient's level of satisfaction with the wheelchair issued.
4. To determine how functional users are in wheelchairs issued in the study setting.
5. Determine the psychosocial impact of wheelchairs issued through the public healthcare system on persons with disabilities
6. To explore relationships between psychosocial needs and wheelchair specification.
7. Describe wheelchair prescription and wheelchair issuing practice as perceived by prescribing health professionals in the study setting.
8. To make recommendations to stakeholders based on the study findings.

### **3.3. Research Design**

A descriptive mixed-method cross-sectional study design was used. The rationale for mixing qualitative and quantitative methods within one study is grounded in the fact that neither quantitative nor qualitative methods are sufficient, by themselves, to capture the trends and details of this specific situation. When used in combination, quantitative and qualitative methods may complement each other and allow for a more robust analysis, taking advantage of the strengths of each (Kroll, Neri & Miller, 2005). It is hoped that this study will allow for a better understanding of the challenges faced by prescribing therapist and wheelchair users living in rural and peri-urban settings.

#### **3.3.1 Phase 1**

During phase one data was collected from wheelchair users. Quantitative methods of data collection and analysis in the form of questionnaires and wheelchair skills tests were used.

#### **3.3.2 Phase 2**

Phase 2 gathered both quantitative and qualitative data from therapists. Data was collected through a questionnaire with open ended questions and semi-structured interviews.

### **3.4 Study setting**

The EC has been classified as a rural province. It is the second largest province in South Africa and covers a wide variety of different terrains including urban, peri-urban and rural terrain. This study was limited to the Western Region of the EC due to time and financial constraints. This region was conveniently selected since the researcher resided and worked in the region.

Figure 1 provides a map of the Western Region of the Eastern Cape. The following cities/towns have community health centres where wheelchairs are issued: Port Elizabeth, Humansdorp, Graaff- Reinet, Somerset- East, Middelburg, Cradock, Uitenhage, Port Alfred and Grahamstown. From all of these settings, outreach were done into smaller towns by district health services occupational- and physiotherapists, and although clients can be referred and assessed for wheelchairs during these outreaches, product preparation, fitting, user training and follow- up/ maintenance are only done at the above mentioned community health centres, due to infrastructure and available resources. Most of the participants for the

current study are situated in the rural and semi-rural areas around Port Elizabeth (distances ranging from 4km to 46km from the closest CHC), with the exception of a participant from a rural area close to Uitenhage (34km from the CHC) and one from a semi-rural area close to Grahamstown (9km from the CHC).



**Figure 3-1 Western Region of the Eastern Cape ([www.roomsforafrica.com](http://www.roomsforafrica.com))**

The home environments for most clients living in a rural and semi-rural setting include soil erosion and uneven hard ground. In some areas there is loose sand and grasslands with hillocks. In most of the semi-rural areas, there are tar roads, whereas the rural areas consist only of gravel roads. The houses in both areas are small and only a few of the houses have tiled or cement floors, the rest consist of gravel floors. In order to keep rainwater from seeping in, most of the houses consist of a raised door panel/ step at the front door – a barrier for a wheelchair user. Some wheelchair users have made adaptations to the entry points of their homes and toilets as best they could. The photos below were taken with the permission of the participants at their homes and are examples of this.





**Figure 3-2 Example of semi-rural dwellings with access to tar road**



**Figure 3-3 Example of a rural dwelling with grass**



**Figure 3-4 Example of “step” to keep rain water out**



**Figure 3-5 Example of self-made ramp to access outside toilet**



### **3.5. Study Population and sampling**

#### **3.5.1 Phase 1**

All adults living in the Western Region of the EC, for whom a wheelchair was issued from June 2010 until June 2012 through the Provincial Government of the Eastern Cape Department of Health (ECDoH) formed part of this study population.

Sampling was done to obtain a sample of both rural and peri-urban wheelchair users in the western region of the EC, as part of the motivation for the study was the concern that urban wheelchairs might be issued in peri-urban and rural settings. An equal number of participants from a rural as well as a peri-urban setting were recruited as these environments are deemed to have a significant impact on user satisfaction with wheelchairs (Donnelly & Carswell, 2002). Due to time and financial constraints, participants were conveniently sampled from the wheelchair database of the Western Region of the EC based on their home address (the closest wheelchair users to the Principal Investigator (PI) living in a rural/ semi-rural area). Participants were contacted until 15 participants from each environment had agreed to take part. Thirty participants (15 per environmental setting) were required to explore relationships between demographic, anthropometric measurements and patient satisfaction scores. Four participants despite agreeing telephonically to participate did not keep their appointments and subsequently a further four who met the criteria were approached. Due to the small sample of convenience, wheelchair users living far from the PI were not included and could have added value to the current study, as these users are even further away from community health centres. Furthermore, a focus-group with the carers of the participants might have allowed for triangulation of results and thereby would have strengthened the findings of the study.

##### **3.5.1.1 Inclusion criteria**

Participants had to comply with the following criteria in order to be included in the study:

- be an adult wheelchair user (i.e. 18 years or older)
- living in a rural / peri-urban environment
- issued his/her wheelchair by the Eastern Cape Health Care System
- have had their wheelchair for at least 3 months

### **3.5.1.2 Exclusion criteria**

Participants were excluded from the study if:

- he/she was a wheelchair user currently using a hired, loaned or wheelchair they bought themselves.

### **3.5.2 Phase 2**

All therapists responsible for the prescription of the wheelchairs of the participants in Phase 1 were invited to participate in this part of the study and were identified following recruitment of participants in Phase 1. Twelve therapists were identified to take part in Phase 2 of the current study. These twelve therapists had prescribed the wheelchairs for the participants used in Phase 1. Two other prescribing therapists could not be identified as there was no signature or prescribing health centre name on the original requisition. From the twelve who could be identified two therapists were unreachable as one had emigrated and another did not return calls despite several attempts. The remaining ten therapists all agreed to take part in the study.

## **3.6 Outcome measures**

### **3.6.1 Phase 1**

The PIADS questionnaire (appendix 1), Functioning Everyday with a Wheelchair (FEW) scale (appendix 2) and a self-compiled wheelchair specification checklist (WSC) (appendix 3) were used for data collection during this phase of the study.

#### **3.6.1.1 PIADS questionnaire**

The Psychosocial Impact of Assistive Devices (PIADS) is a standardised questionnaire used to assess the suitability of assistive devices as well as the satisfaction of the user of the assistive device (Jutai, 1999). It was developed by H. Day & J. Jutai (1996). The priority was to create a scale that would reliably measure perceived device impact and discriminate among device categories and user conditions in a clinically sensible way (Day, Jutai & Campbell, 2002). It has been translated into various languages including English, Afrikaans and isiXhosa and used in multiple settings to assess the impact of assistive devices (ranging from hearing aids to mobility aids) on users and on caregivers. The basic psychometric properties of the PIADS were described by Day & Jutai (1999), based on a sample of eyewear users

(n=307). Stability of the scale, construct validity and discriminative validity were all demonstrated in that the Pearson correlation coefficients (rp) were significant at the 0.05 level between the PIADS subscales and the Pleasure (rp 0.46 to 0.59) and Dominance subscales (rp 0.21 to 0.34) but not with the Arousal subscale (rp 0.06 to 0.17); showing that these scales are unrelated and were designed to measure theoretically different concepts (Day, Jutai & Campbell, 2002).

In 2004 the scale was used to assess the quality of life of wheelchair users with Multiple Sclerosis. The PIADS was found to be clinically useful for exploring person-environment interactions in this study (Devitt, Chau & Jutai, 2004). The PIADS questionnaire was therefore deemed appropriate for evaluating the impact of the wheelchair on well-being and quality of life. In the current study, this scale was used to determine what the client's as well as the caregiver's perceived level of satisfaction is with the wheelchair.

### **3.6.1.2. FEW scale**

The FEW scale (Mills, Holm & Schmeler, 2003) was used to assess participants' functionality in their wheelchair. The scale consists of three parts: Functioning Everyday with a Wheelchair (FEW/FMA questionnaire), Functioning Everyday with a Wheelchair- Capacity (FEW-C) and Functioning Everyday with a Wheelchair Performance (FEW-P). The FEW/FMA was designed as a self-report questionnaire to be administered to consumers of seating-mobility technology, as a dynamic indicator or profile of perceived user function related to wheelchair use. The FEW-C focuses on wheelchair user's capacity to perform tasks or activities (e.g., mobility, reach, transfers) in a controlled clinical environment. The FEW-P focuses on wheelchair user's participation and performance of activities in life situations (e.g., mobility, domestic and community life, work and employment) in their actual environment (home/community). The measure includes evaluation of basic wheelchair biomechanics as well as functionality of the client and wheelchair dexterity skills. Both instruments are matched to the FEW (FMA) questionnaire in that the items on the FEW-P/FEW-C are identical to the self-report items on the questionnaire. The FEW-C and the FEW-P are designed to measure function based on the International Classification of Functioning, Disability, and Health (ICF) constructs of capacity and performance, respectively. The FEW-C and FEW-P were administered interchangeably, depending on the test setting (clinic/ home-visit) and it was therefore deemed appropriate to use this outcome measure in the current study.

### **3.6.1.3. Wheelchair Specifications: a Checklist (WSC)**

A questionnaire with standard checklist (appendix 3) regarding suitability and correctness of the wheelchair for the client in all aspects of life was designed by the researcher. The questionnaire consists of two sections: Section A which collates demographic data such as diagnosis, period client has been in their current wheelchair and medical history i.e. pressure sores; and Section B is a checklist compiled from the standards for wheelchair prescription (PGWC DoH, 2009a) to establish whether or not the wheelchair was appropriately prescribed. Section B consists of five categories namely: Size, Environment, Postural Support, Function and Biomechanics. Evaluation of the size of the wheelchair was conducted by re-measuring the user. Postural supports were assessed by critically evaluating the seated posture, the finger- test (assessing the pressure of the ischial tuberosities on the wheelchair cushion by using of the investigators fingers), as well as incorporating the items assessed during the FEW-C/ FEW-P. Environment, Function and Biomechanics was scored after critically assessing the results of the FEW-C/ FEW-P. This checklist was peer- reviewed by expert seating specialists (S. Visage<sup>2</sup> and C. Hubbard<sup>3</sup>).

## **3.6.2 Phase 2**

### **3.6.2.1 Open ended questions and Semi-structured interview for therapists**

The semi-structured interview (appendix 4) consisting of questions relating to the criteria typically used by health professionals when prescribing a wheelchair (DiMarco, Russel & Masters, 2003) was used to determine health professionals' knowledge on wheelchairs available on tender and their perception of the appropriateness of their wheelchair prescription practice. This method was chosen in that it promotes a positive rapport between interviewer and interviewee (simple, efficient and practical way of getting data about things that can't be easily observed i.e. feelings) and was also thought to maximise the probability of identifying a broad range of beliefs and ideas as it applies to the issuing of wheelchairs in the Western Region of the EC. Furthermore it has a high validity as participants are able to talk directly and in depth about the motives behind their actions. With few pre-set question the researcher is unable to pre-judge what is and what is not important (Bradley, 2007).

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<sup>2</sup> MSc Rehabilitation Sciences, US; Co-editor of seating course manual.

<sup>3</sup> BScOT; Manager CE Mobility EC.

### **3.7. Pilot Study**

A pilot study to determine understanding and readability of the questionnaires as well as interview questions was conducted. The WSC was also piloted to ensure its comprehensiveness. The pilot study was performed with two wheelchair users and two therapists. Their data was not included in the final analysis.

During the implementation of the pilot study it was seen that the questionnaires were understandable and the assessment instructions were easy to follow provided a translator was used for isiXhosa participants. The value of home visits was clearly seen during the pilot study, and was it not for time and financial constraints all of the wheelchair user assessments would have been done via home visits. No amendments were made to any of the outcome measures as all were adequate and proved to provide suitable data so as to meet the aims and objectives. The WSC proved comprehensive.

This pilot trial also provided opportunity to determine the time taken to complete the battery assessment which aided in planning. It was found that each assessment took 2 – 3 hours.

### **3.7. Procedure**

Following approval by the Research Ethics Committee (Stellenbosch University), the Department of Health and institutional heads of participating Day Hospitals, participants were contacted regarding their willingness to participate.

#### **3.7.1. Phase 1**

Participants were invited telephonically to participate in the study. An appointment was made for the evaluation, either via home visit or an outpatient appointment. There the researcher accompanied the clients and caregivers to a quiet room to collect data. Each participant was asked to provide written informed consent (Appendix 5). Those who agreed to partake in the study were then asked to complete section A of the WSC, the FEW/FMA questionnaire and the PIADS questionnaire. After completing the questionnaires, the WSC and the FEW-C/ FEW-P were administered by the principle investigator. All of the above were administered by the PI and where language was a barrier a translator was used to give the instructions in isiXhosa.

From these participants a list of the clinics where the wheelchairs were issued was obtained and prescribing therapists were invited to participate in the next part of the study.

### **3.7.2. Phase 2**

Therapists were contacted and the nature of the study was explained. Willing participants were requested to sign an Informed Consent Form and complete a semi-structured interview (Appendix 4) which evaluated the therapists' knowledge, perspective, beliefs and ideas regarding the criteria used to issue wheelchairs for their client. These interviews were all done one-on-one by the researcher at a time and place convenient for the therapist. All interviews were conducted on the premises of the relevant HC centre.

## **3.8. Data Processing and Analysis**

The analysis was done in consultation with a statistician from the Centre of Statistical Consultation of Stellenbosch University.

### **3.8.1. Phase 1**

Scores for the 3 subscales of the PIADS Q i.e. competence, adaptability and self-esteem were calculated by adding the values corresponding to specified items (Day & Jutai, 1997). A high positive total of the sum of the three subscales would indicate a positive impact on the client's quality of life. These scores were entered into an Excel spread sheet and checked for human errors.

Scores for the FEW/FMA scale were calculated by adding the values as it corresponds to specific items. The FEW/FMA consists of 10 self-report items which are scored using a 6 point scale of 6 = completely agree to 1 = completely disagree, and a score of 0 = does not apply. The FEW-C and FEW-P consist of 10 criterion-referenced, performance-based tasks, which are identical to the 10 FEW/FMA items. The performance-based items yield three distinct category scores, independence, safety, and quality, and summary scores based on a predefined 4 point ordinal scale.

The WSC was coded and analyzed by the researcher according to the literature and was based on a 3 point ordinal scale (with 1 being the worst score and 3 being the best score). The knowledge items were scored according to criteria determined by the researchers, as derived from the literature (WCPG DoH, 2009a; WCPG DoH, 2009b; DoH, 2000). Descriptive

statistics, viz. averages and standard deviations or medians and percentiles for continuous data, and frequencies and percentages for categorical data were computed and displayed in graph/histogram or table format in Chapter 4.

Relationships between variables were tested by using Pearson/Spearman correlation for ordinal variables, ANOVA for comparing ordinal variables between groups, and the Chi-square test where categorical variables needed to be compared. A p- value of less than 0.05 was deemed statistically significant.

### **3.8.2. Phase 2**

The interviews were electronically recorded and transcribed by an external scribe. The transcribed data was checked by a peer to identify themes and these themes were then compared to the themes that the principal investigator had identified. Content Analysis was done according to predetermined themes that had been established in accordance with the study problem namely Feelings, Challenges and Experiences. At the same time analysis for emerging themes was allowed for. The different themes were highlighted in different colours, e.g. the challenge of Funding was highlighted in green on all the transcripts and coded as “Funding” (Shannon & Hsieh, 2005). Number of responses was added for the quantitative open- ended questions and data was reported both narratively and in table format. The data analysis method has been clearly described to ensure that the research is both transparent and explicit (Russell, Gregory, Ploeg, DiCenso, & Guyatt, 2005).

### **3.8.3. Rigor**

Triangulation of findings was done through triangulation of sources and triangulation of measuring instruments. Data was collected from therapists and users. In addition data on function was collected through user scored tool and a tool that was scored by the researcher.

## **3.10. Ethical Considerations**

The following ethical aspects were addressed:

- The proposal was externally reviewed and approved by the Ethics Committee for Human Research at the Faculty of Health Sciences, Stellenbosch University (Ethics approval number: S12/08/231, Appendix 5)

- A letter of request in which reasons for undertaking this study as well as all study procedures are described was sent to the hospitals and Community Health Centre's in the Eastern Cape. Permission was granted by the DoH and relevant institutional heads (Appendix 6)
- Written informed consent (Appendix 7) was obtained from each participant (therapists and wheelchair users and or caregivers) for the execution of the study in which the following was stated:
  - ✓ How participant anonymity and or confidentially will be ensured
  - ✓ That all participants have a right to withdraw without consequences
  - ✓ That the finding will be reported to all interested parties i.e. The Eastern Cape Department of Health, the Orthotics & Prosthetics' center in the Western region of the Eastern Cape and participants of the study.
  - ✓ The participants may receive the results of the study upon request.
  - ✓ The proposal was externally reviewed and approved by the Ethics Committee for Human Research at the Faculty of Health Sciences, Stellenbosch University.
  - ✓ Written permission was obtained from the Medical Superintendent where the clinic evaluations of the wheelchair users were done as well as the physiotherapist in charge of the hospital where the study was executed.
  - ✓ There were no foreseeable risks involved in conducting this study.
  - ✓ Participants were not paid to take part in this study, however all travelling expenses (when applicable) were reimbursed to the participants.

### **3.11. Summary**

In order to reach the aims and objectives of this study a mixed method study design was needed. The procedure involved using a variety of outcome measures to collect quantitative and qualitative data as neither would have been able to address the research question in a solitary capacity. The results obtained from the implementation of the above will be conveyed in Chapter 4.



# *Chapter 4*

## **RESULTS**

This chapter presents the results of this study in accordance with the study objectives. Sample demographics will be presented first followed by the findings related to whether wheelchair users perceive their wheelchairs to meet their needs (Phase 1). Correlational analysis as to correct wheelchair prescription (Phase 1) is followed by a report of the interviews with prescribing therapists (Phase 2).

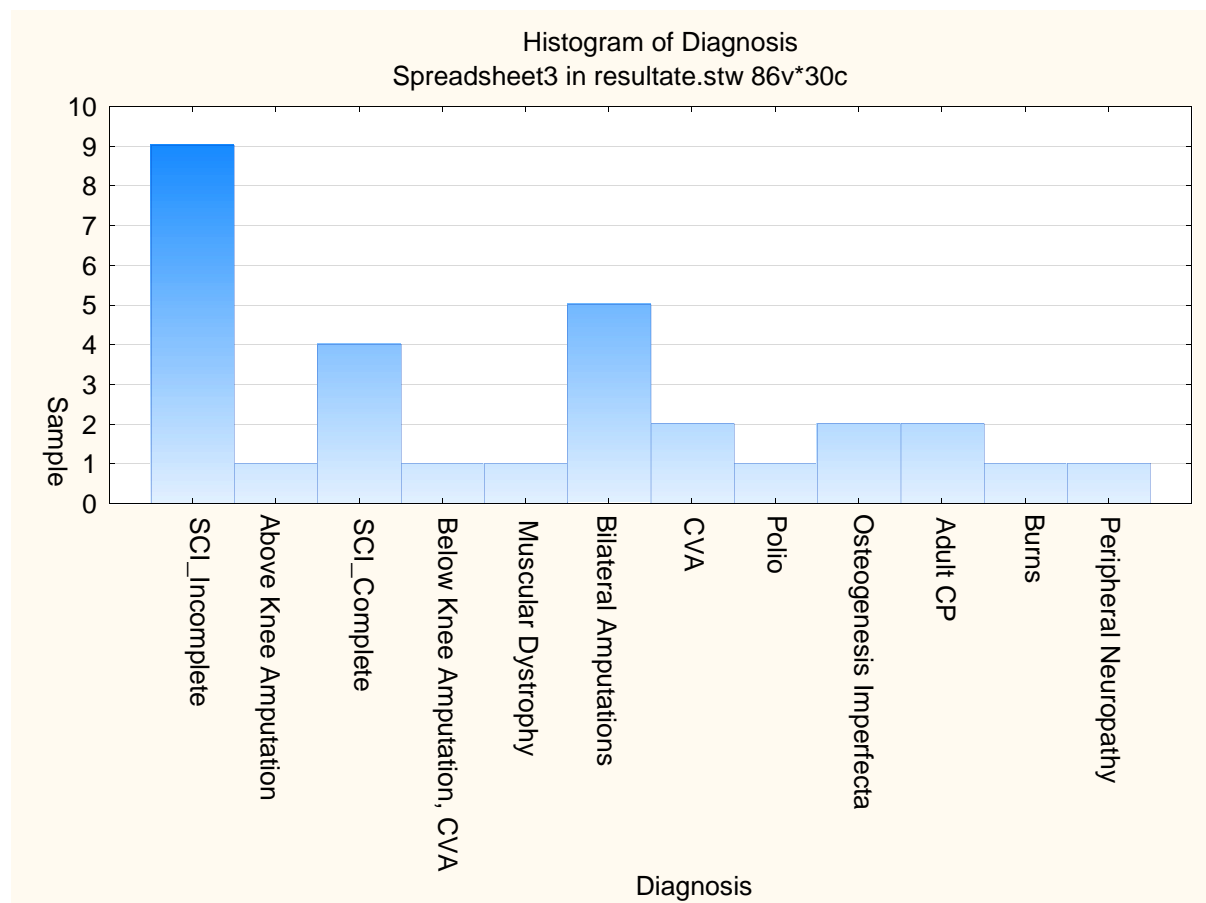
### **4.1 Phase 1**

#### **4.1.1 Subject characteristics**

As this was a sample of convenience; enrolment continued until 15 wheelchair users from both rural and peri-urban settings (total of 30) were entered into the current study.

Of the 30 participants, six (20%) were female and 24 (80%) were male. The mean age of the participants was 43.4 years, with a minimum age of 19 and a maximum age of 82 years.

The majority of the participants (9/30) had an incomplete spinal cord injury (SCI), followed by bilateral amputations (5/30) (Figure 4.1).



**Figure 4-1 Sample demographics: Diagnoses (n=30)**

#### **4.1.1.1 Wheelchair (wc) size and type**

Table 4.1 shows the number and type of wheelchairs issued to participants (n=30).

**Table 4-1 Type of Wheelchair issued**

CE Cruiser	Econorigid	Roughrider	All Terrain Wheelchair (ATW)
Urban wheelchairs		Semi rural/ Peri- urban wheelchairs	
17	8	3	2

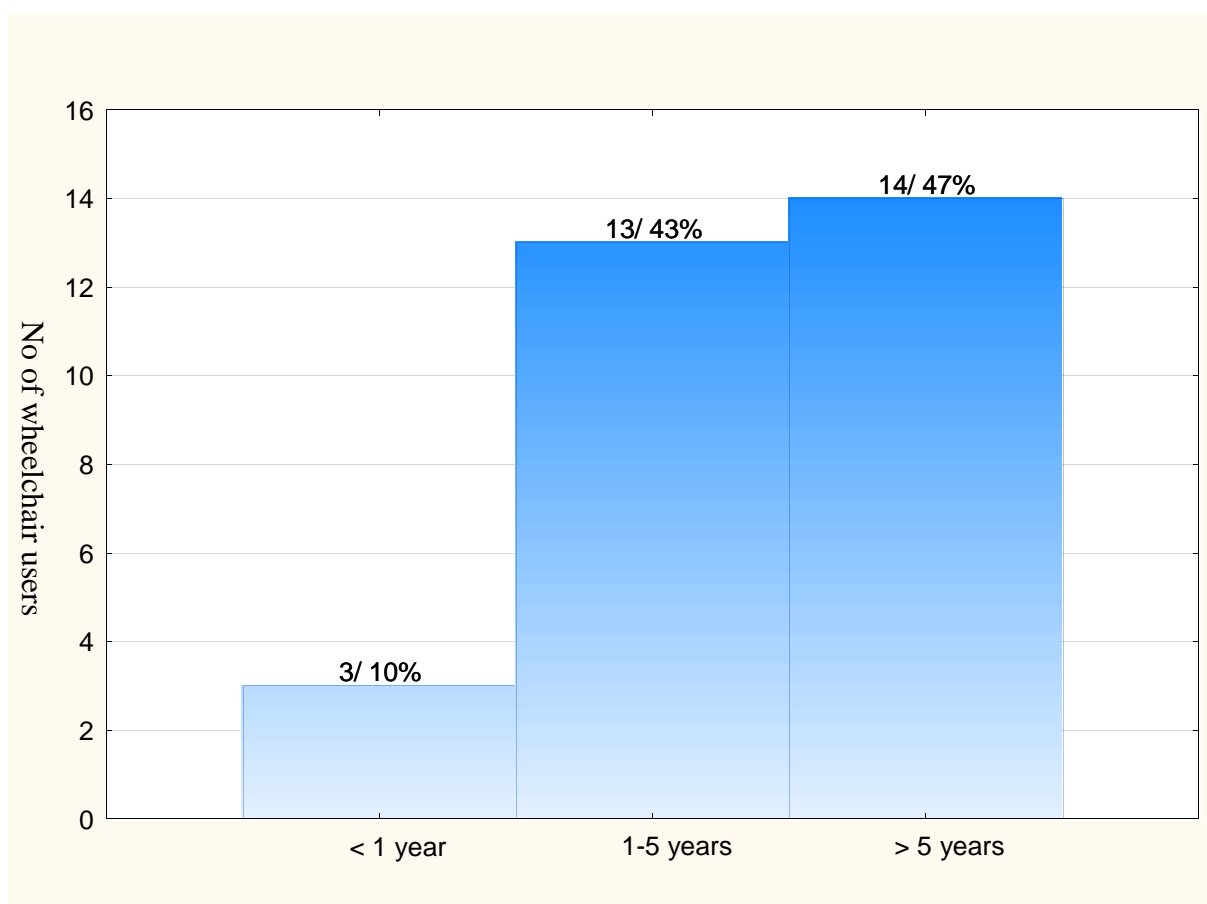
The sizes of the wheelchairs issued ranged from 12 inches to 20 inches, with the majority of participants using a 16 inch wheelchair (12 (40%)). Of the 30 participants 25 (83%) were currently using a wheelchair classified as an ‘urban’ wheelchair and the remaining 5 (17%) of participants were using a ‘semi-rural’ wheelchairs. None of the participants were using a ‘rural’ wheelchair.

#### **4.1.1.2. Wheelchair cushions and pressure sore history**

Seven (23%) of the participants were not using a wheelchair cushion at the time of the assessment. Nine (37%) were using a thick pressure care cushion and the remaining 14 (47%) were using a thin positioner. Furthermore, 23% of the participants reported that they either currently had a pressure sore or previously had suffered from a pressure sore.

#### **4.1.1.3. Total years in wheelchair and hours spent in wheelchair**

Figure 4.2 shows how many years the participants had been using the wheelchair they were currently using at the time of the assessment.



**Figure 4-2 Total years in current Wheelchair**

As seen in Table 4.2 the majority of participants spent a lot of time in their wheelchairs daily.

**Table 4-2 Hours spent in Wheelchair**

Hours spent in wc daily	Participants (n=30)
>8	11
6 – 8	11
4 – 6	5
<4	3

#### **4.1.1.4. Mode of transport**

Table 4.3 is a representation of the different modes of transport that the participants made use of. Thirteen (43%) wheelchair users communicated that they were forced to make use of hiring private cars to be able to transport their wheelchairs to hospital, clinics and other places as some taxis were unwilling to transport the wheelchairs as well.

**Table 4-3 Mode of Transport**

	Hired Car	Taxi	Car/ Taxi	Bus/ Taxi
<b>Semi- Rural</b>	7	5	2	1
<b>Rural</b>	6	4	3	2

#### **4.1.1.5. Home Visits**

Two (7%) of the participants had ever had a home visit from a therapist or medical professional.

#### **4.1.2. Suitability (correct fit/match) of wheelchairs prescribed**

This question was investigated using the Functional Mobility Assessment (FMA- refer to chapter 3). Participants awarded a score between 0% and 100% (at 20% intervals) to each item (see table 4-4). These scores were added and means/ medians were calculated. Most of the participants scored high on the FMA, with the summary mean for the 10 items being 0.74 and the median 0.77. The standard deviation was 1.88386 with a Cronbach alpha of 0.85. These findings suggest that >50% of wheelchair users were >80% satisfied regarding functionality in their wheelchairs. Transport however was predominantly perceived as problematic with 19 of the participants being <60% satisfied with their wheelchair in terms of transport.

**Table 4-4 Participant rating of wheelchair functionality as determined by the FMA**

Criteria	100%	80%	60%	40%	20%	0%
To carry out activities of daily living	12	5	5	3	4	1
Comfort Needs	11	10	4	2	1	2
Health Needs	15	7	3	4	0	1
Independence, Safety & Efficiency	13	5	6	2	3	1
Reach	17	3	4	2	3	1
Transfers	16	6	4	2	1	1
Personal Care	17	3	5	3	1	1
Indoor Mobility	11	7	9	1	2	0
Outdoor Mobility	7	11	7	0	3	2
Transport	6	5	11	2	4	2

A repeated measures ANOVA test revealed no significant difference for the FMA scores between subjects from a rural environment and those from a semi-rural environment ( $p=0.17$ ). Furthermore, no significant difference was found when compared to type of wheelchair as seen in Figure 4.3 and Figure 4.4 below.

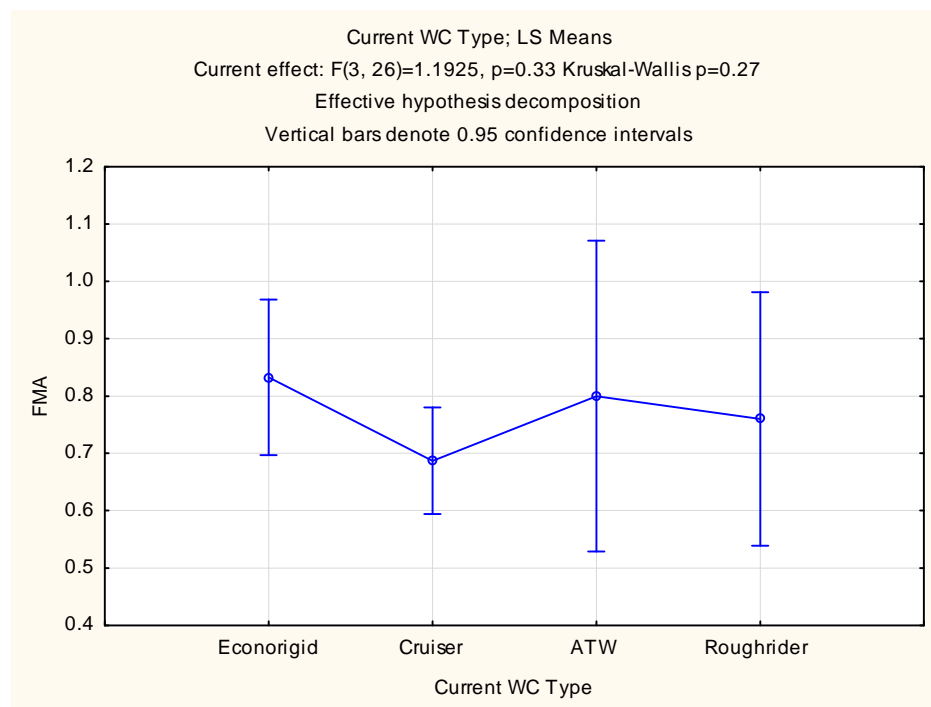
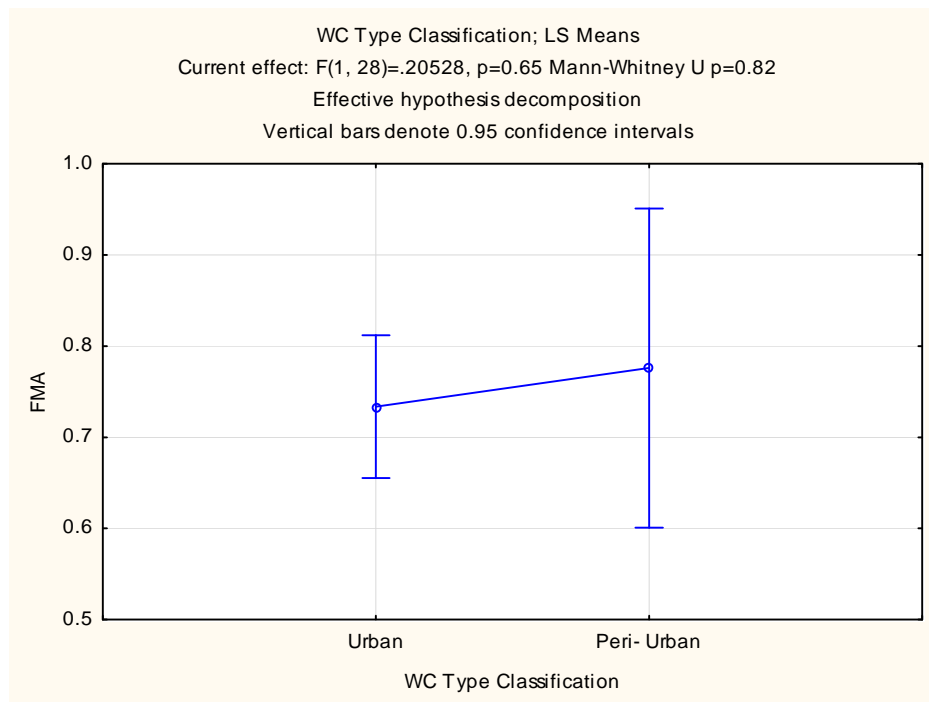
**Figure 4-3 FMA and type of wheelchair**

Figure 4.3 shows that the ATW had the biggest range of scores with a combined lowest score as well as the highest score for functionality in the wheelchair. The Cruiser had the lowest average while the Econorigid had the highest average score. Although the p- value derived was not statistically significant, challenges with the Cruiser is shown and will be discussed in Chapter 5.



**Figure 4-4 FMA and Wheelchair type classification**

### **4.1.3. Independence, safety and quality**

The FEW scale is divided into three sub score categories namely: Independence, Safety and Quality. Each sub category is given a score between 0 and 3 (0 being the lowest and 3 the highest). All of the tasks are exactly as the FMA items discussed above.

#### **4.1.3.1. Independence**

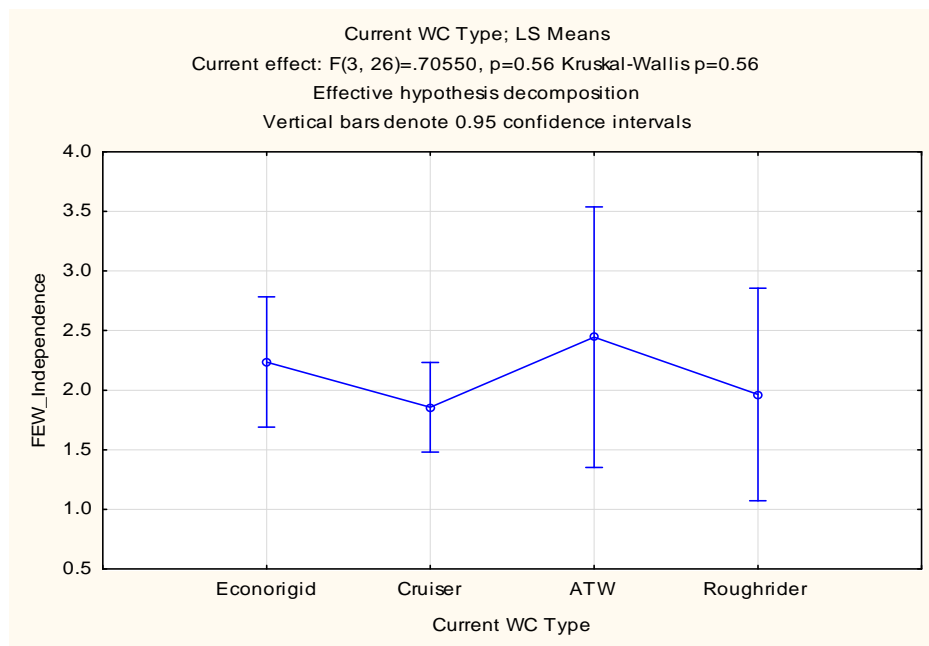
The independence scores were awarded by the principal investigator by observing to which degree of independence each participant administered each of the nine tasks. This was done by circling on the score sheet, each verbal assist, visual assist and physical assist that the investigator had to give during the course of the task. A maximum of three assists were allowed in each assist category before moving down a value i.e. if the investigator gave three

verbal assists and the participant still struggled with the task, a visual assist would be given (“let me show you how”) and the score automatically went down from a 3 to a 2. Any form of physical assist automatically meant a score of 0. The following table summarizes the scores achieved by the participants (n=30).

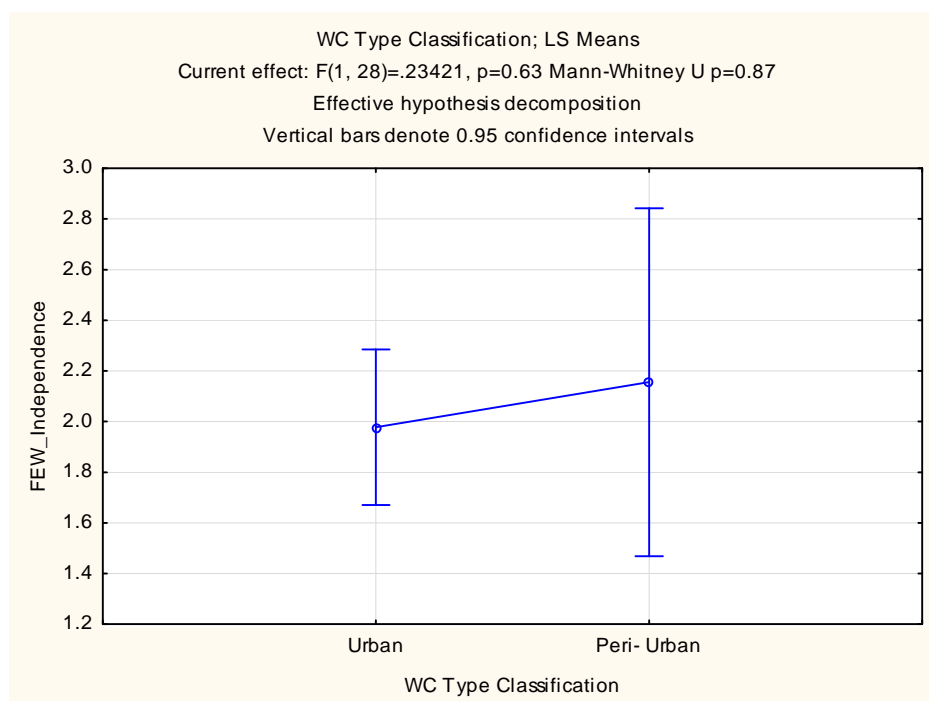
**Table 4-5 Participant rating for FEW Independence**

Criteria	Score categories (FEW Independence)			
	3	2	1	0
Comfort needs	21	7	1	1
Health needs	20	6	3	1
Operate wc	18	7	1	4
Reach	24	1	4	1
Transfer	16	3	4	7
Personal Care	23	1	2	4
Indoor Mobility	16	4	3	7
Outdoor Mobility	9	1	3	17
Transport	4	1	6	19

Participants scored good independence scores for the categories comfort needs, health needs, reach and personal care. The categories outdoor mobility and transport scored the lowest and therefore appear to be problem areas with regards to independence specifically. When the Independence scores were compared to the type of wheelchair the users were using, no significant difference was seen (Figure 4.5), although the peri-urban wheelchairs did reveal a higher 0.95 confidence interval than the urban wheelchairs (Figure 4.6).



**Figure 4-5 FEW (Independence) and type of wheelchair**



**Figure 4-6 FEW (Independence) and wheelchair classification**

#### 4.1.3.2. Safety

For this sub category of the FEW, the principal investigator awarded a score between 0 and 3 relating specifically to the safety of each task. A score of 3 meant that safety standards were adequately met, a score of 2 meant there was minor risk to the participant when doing the

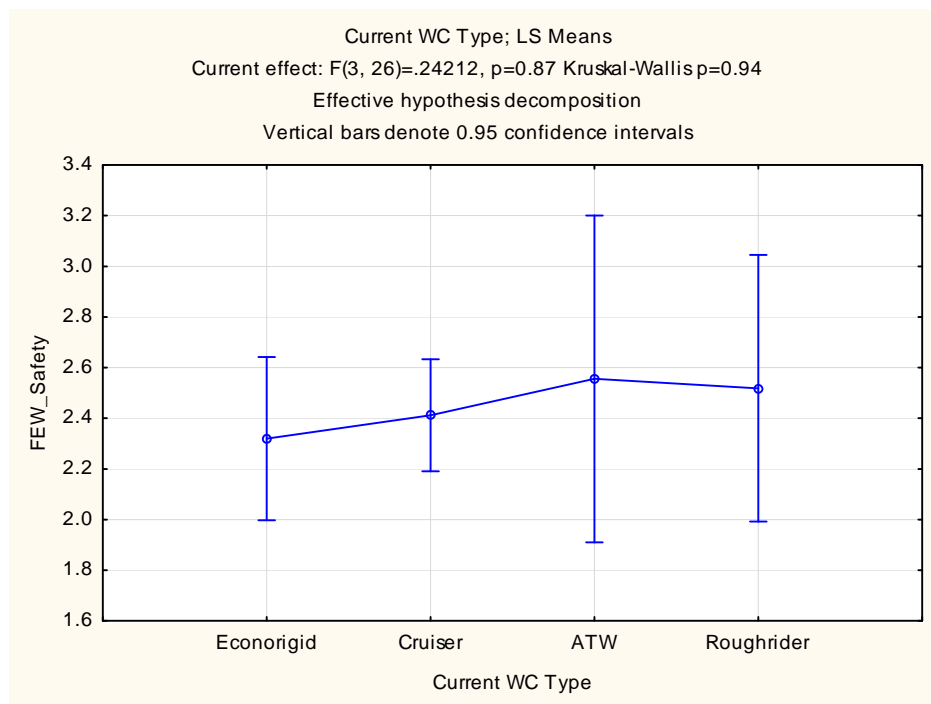


task, a score of 1 was awarded when the investigator had to step in in order to prevent harm and a score of 0 meant there was severe risk to the participant and the task was discontinued completely to prevent this. The following table summarizes these safety scores (n=30)

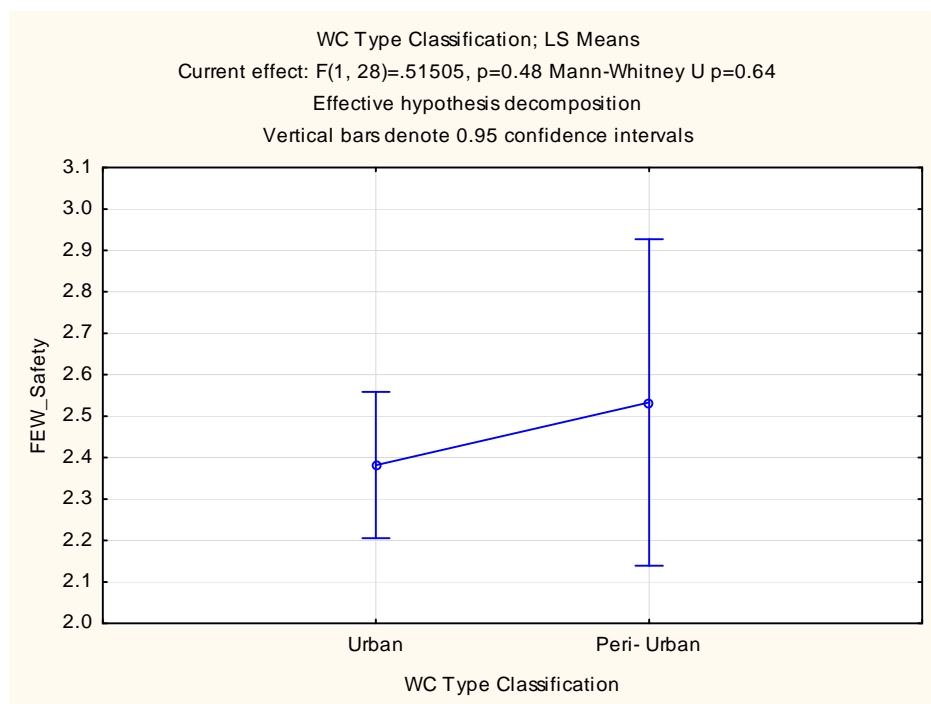
**Table 4-6 Participant rating for FEW Safety**

Criteria	Score categories (FEW Safety)			
	3	2	1	0
Comfort needs	19	8	3	0
Health needs	23	3	2	2
Operate wc	18	3	3	6
Reach	21	9	0	0
Transfer	13	11	5	1
Personal Care	26	3	0	1
Indoor Mobility	25	2	1	2
Outdoor Mobility	10	11	5	4
Transport	14	11	2	3

The category ‘Operate Wheelchair’ scored the lowest in this FEW Safety measure, due to the fact that it involved activating and releasing the brakes on the wheelchair and many participants had either no brakes or only one brake which automatically meant a safety score of 0. No significant difference was seen when the FEW was compared to the type of wheelchair (Figure 4.7) or the wheelchair type classification (Figure 4.8).



**Figure 4-7 FEW (Safety) and type of wheelchair**



**Figure 4-8 FEW (Safety) and wheelchair type classification**

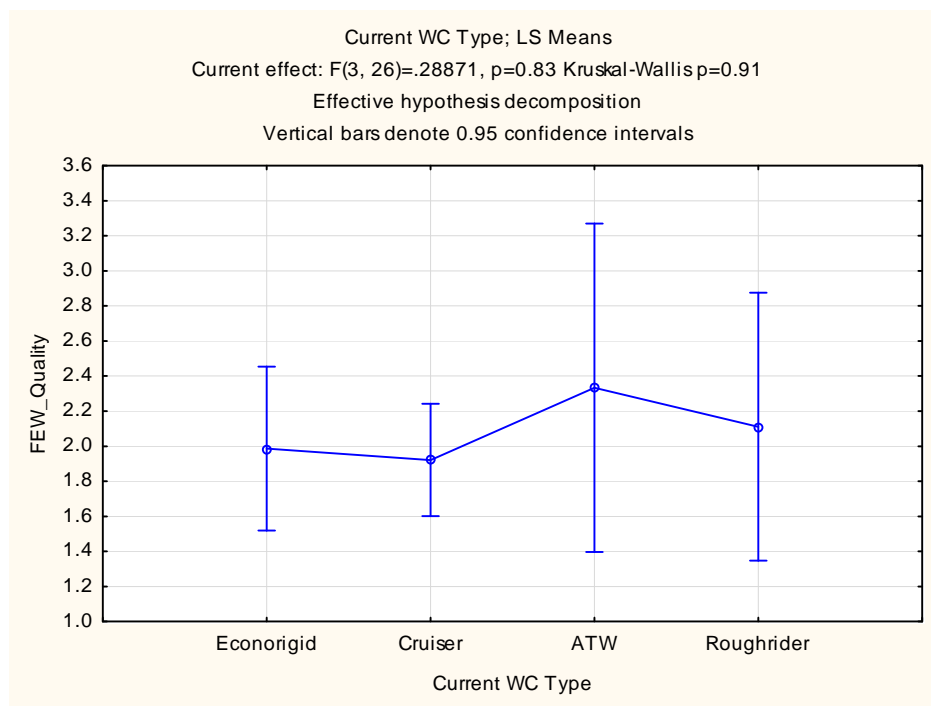
#### 4.1.3.3. Quality

For this sub category score of the FEW, the investigator awarded a score for the quality with which the task was being administered. A score of 3 was awarded when the participant met the standards of the task. If improvement was still possible for the specific task even though the standards were met, the investigator awarded a score of 2. A score of 1 was awarded if standards were only partially met and a score of 0 meant that standards were not met at all. Table 4.7 summarizes these Quality scores.

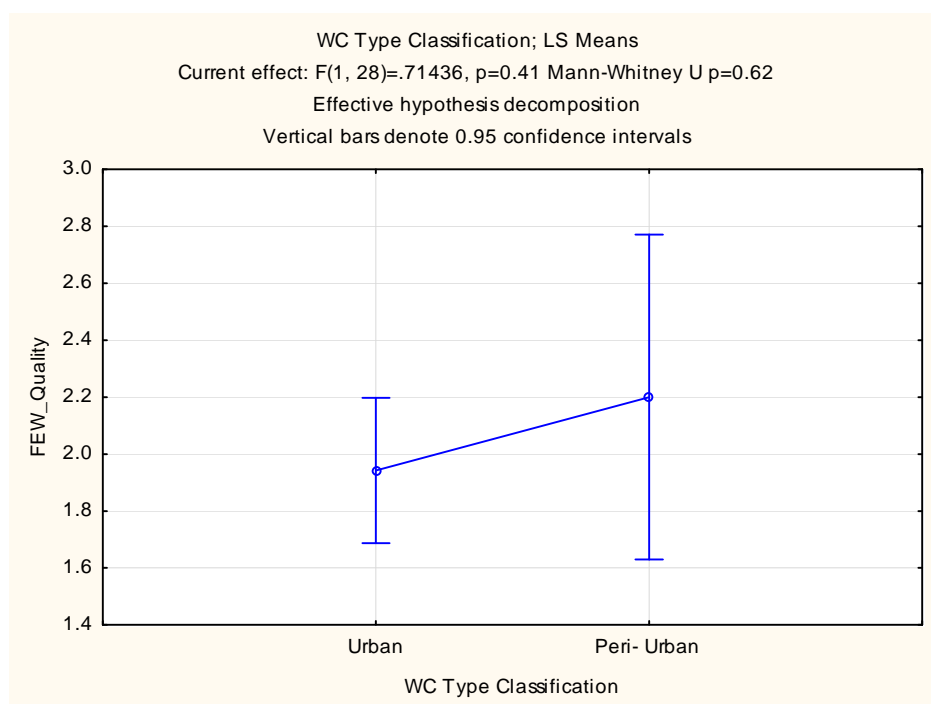
**Table 4-7 Participant rating for FEW Quality**

Criteria	Score categories (FEW Quality)			
	3	2	1	0
Comfort needs	19	9	2	0
Health needs	15	8	1	6
Operate wc	12	7	1	10
Reach	21	4	4	1
Transfer	16	9	4	1
Personal Care	22	2	3	3
Indoor Mobility	16	5	6	3
Outdoor Mobility	3	7	10	10
Transport	1	5	18	6

Again the category operate wheelchair was a problem for the same reason as stated under Safety. The quality scores for Outdoor Mobility and Transport were also low and will be discussed in Chapter 5. For this category of the FEW, no significant difference was found when the type of wheelchair was compared to the scores achieved (Figure 4.9) or when the wheelchair type classification were compared with the FEW Quality scores (Figure 4.10). Figure 4.9 and 4.10 shows that participants using peri urban wheelchairs had slightly higher average scores on the quality of tasks than those using urban wheelchairs. In addition the highest score for peri-urban chairs were a bit higher than for urban chairs.



**Figure 4-9 FEW (Quality) and type of wheelchair**



**Figure 4-10 FEW (Quality) and wheelchair type classification**

#### 4.1.4. Wheelchair Specifications Checklist (WSC)

The WSC was used by the principal investigator as a checklist incorporating all aspects of wheelchair seating and dexterity skills as assessed with the previous scales, so as to get an

overall score of whether or not the participant was using the most appropriate wheelchair for his/ her lifestyle, environment and anatomical/ biomechanical build. It is divided into five sections, and for each section a score was awarded between 1 and 3 (1 being the lowest score and 3 the highest score).

#### **4.1.4.1. Size**

Seventeen participants' wheelchairs were the correct size according to their body measurements as determined by the WSC measure (Table 4.8), and one participant had a completely inappropriate wheelchair as far as size was concerned.

**Table 4-8 No of participants and wheelchair size (as determined by the WSC)**

<b>Size</b>	<b>Participants (n=30)</b>
Correct	17
2 or less inches big or small	12
>2 inches big or small	1

#### **4.1.4.2. Environment**

Again, a score between 1 and 3 was awarded relating to whether or not the current wheelchair of each participant suited the environment within which they had to operate and live every day (Table 4.9).

**Table 4-9 Participant rating regarding Environment and wheelchair suitability (as determined by WSC)**

<b>Environment</b>	<b>Participants (n=30)</b>
Suitable	8
Suited to one aspect of environment	17
Not suitable to any area of environment	5

#### **4.1.4.3. Function**

Independent functioning within the wheelchair was assessed (Table 4.10)

**Table 4-10 Over-all independent functioning within the wheelchair (as determined by WSC)**

Function	Participants (n=30)
Wheelchair improves function	12
Wheelchair does not improve or impair function	10
Wheelchair impairs function	8

**4.1.4.4. Postural Support**

A score between 1 and 3 was awarded for each participant depending on whether or not postural supports had been adequately taken into account at the issue and seating of their wheelchairs. Results are seen in the table below:

**Table 4-11 Overall adequacy and appropriateness of postural supports of the wheelchair (as determined by WSC)**

Postural Support	Participants (n=30)
Adequate	10
Limited postural supports added	12
No postural support	8

**4.1.4.5. Biomechanics**

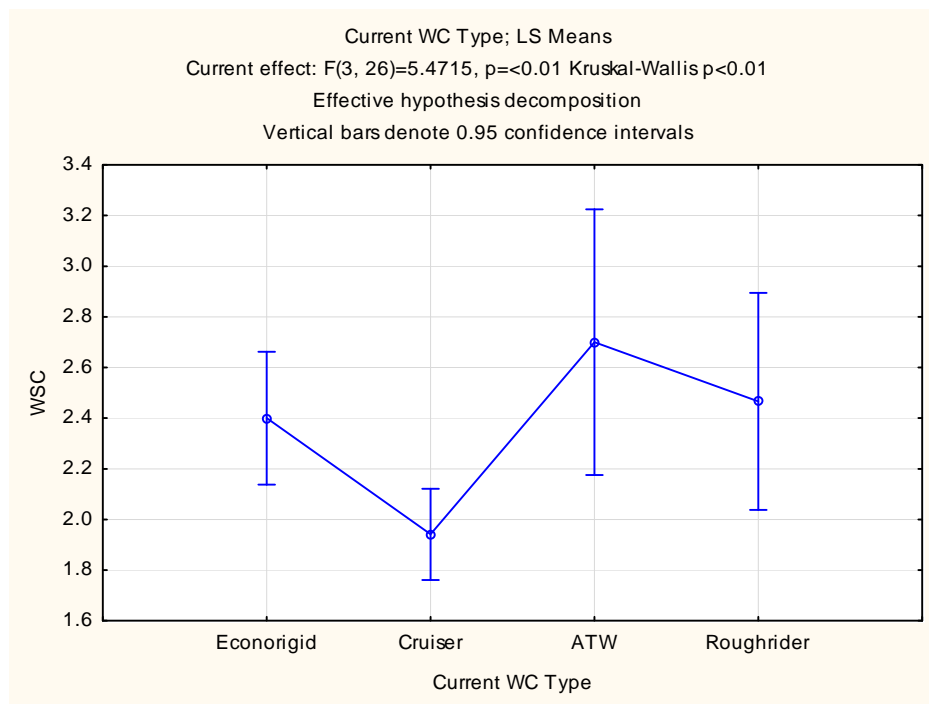
Lastly, based on the scores derived from the FEW as well as the finger pressure test, a score between 1 and 3 was awarded to each participant relating to whether or not the biomechanics of the wheelchair user had been taken into account. The results are shown in the Table 4.12.

**Table 4-12 Overall adequacy of patient and wheelchair biomechanics match (as determined by WSC)**

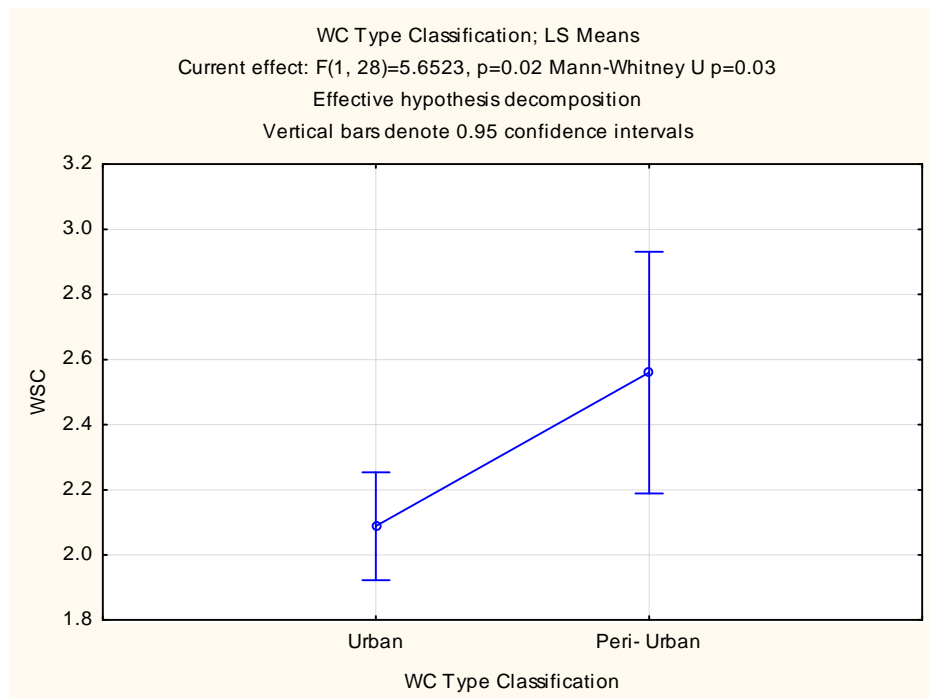
Biomechanics	Participants (n=30)
Suitable	5
Taken into account but to limited extent	20
Not addressed	5

As seen in Figure 4.10 and Figure 4.11, when the WSC scores were compared with the type of wheelchair, a significant difference was found ( $p < 0.01$ ). The peri-urban wheelchair types

achieved significantly higher scores than the urban type wheelchairs ( $p=0.03$  during a Mann-Whitney statistical analysis).



**Figure 4-11 WSC and type of wheelchair**



**Figure 4-12 WSC and wheelchair type classification**

#### 4.1.5. Satisfaction of participants with their wheelchair

Table 4.13 shows the self-reported weighting scores of how participants rated various psycho-social aspects of their wheelchair functioning and experiences. A value of -3 means that the participant is completely unsatisfied with the impact of their wheelchair on that specific area of their lives, whereas a value of 3 means that the participant was completely satisfied with the effect their wheelchair has on that area of their life e.g. Competence. A value of 0 means that the participant's wheelchair did not either increase or decrease that area of their life (e.g. Happiness – the wheelchair does not make them more or less happy).

**Table 4-13 The Psycho-social impact of the wheelchairs on the users (n=30)**

	-3	-2	-1	0	1	2	3
<b>1. Competence</b>	4	2	2		4	8	12
<b>2. Happiness</b>	1	1	4		2	7	15
<b>3. Independence</b>	2	3	1	1	4	8	11
<b>4. Adequacy</b>	2	3	2		4	13	6
<b>5. Confusion</b>	4	1	3	7	4	2	8
<b>6. Efficiency</b>	2	1	1		7	9	10
<b>7. Self-Esteem</b>	2	2			2	5	18
<b>8. Productivity</b>	2	2	1	2	3	6	13
<b>9. Security</b>	1	1	1	1	3	7	16
<b>10. Frustration</b>	5	5	2	5	3		10
<b>11. Usefulness</b>	1	1	1	1	2	8	16
<b>12. Self-Confidence</b>		2			2	5	21
<b>13. Expertise</b>		2	4	4	3	5	12
<b>14. Skilfulness</b>		2	3	3	6	5	11
<b>15. Well-Being</b>	2	3	2	2	2	7	12
<b>16. Capability</b>	1	2	1	2	4	6	14
<b>17. Quality of Life</b>	1	1	2	2	2	11	11
<b>18. Performance</b>	1	4	2		2	8	13
<b>19. Sense of Power</b>	2	3	2	2	1	5	15
<b>20. Sense of Control</b>		5	2	1	4	4	14
<b>21. Embarrassment</b>	5	4		4	3	3	11
<b>22. Willingness to take chances</b>	2	1		2	2	6	17
<b>23. Ability to Participate</b>	1	1	2		2	6	18
<b>24. Eagerness to Try New Things</b>	1	2		1	2	4	20



25. Ability to adapt to ADL	2		2	1	1	7	17
26. Ability to take advantage of opportunities		2		1	3	9	15

The scores of the PIADS are summarised in the table above. The PIADS is divided into three subscales and scores for each subscale are calculated. The *Competence* subscale is derived by adding the values corresponding to items 1, 3, 4, 6, 8, 11, 13, 14, 16, 17, and 18, subtracting the value corresponding to item 5 and dividing the total by 12. The *Adaptability* subscale is derived by adding the values corresponding to items 15, 22, 23, 24, 25, and 26 and dividing the total by 6. The *Self-esteem* subscale is derived by adding the values corresponding to items 2, 7, 9, 12, 19, and 20, subtracting the values corresponding to items 10 and 21 and dividing the total by 8.

Results and descriptive statistics for this are as follows:

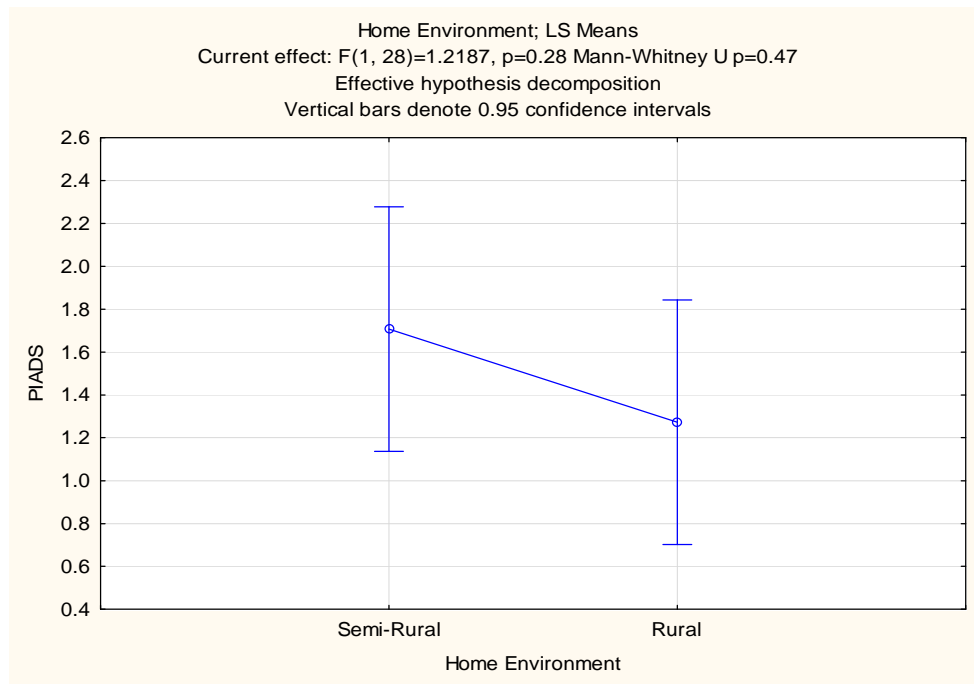
**Table 4-14 Summary scores PIADS**

	Median	Minimum	Maximum
<b>Competence</b>	1.54	-1.5	3.0
<b>Adaptability</b>	2.17	-2.67	3.0
<b>Self- Esteem</b>	1.19	-0.63	3.0

The participants scored the highest in the Adaptability category, although this sub category also had the widest range between minimum and maximum scores. The lowest summary scores were found in the Self- Esteem category.

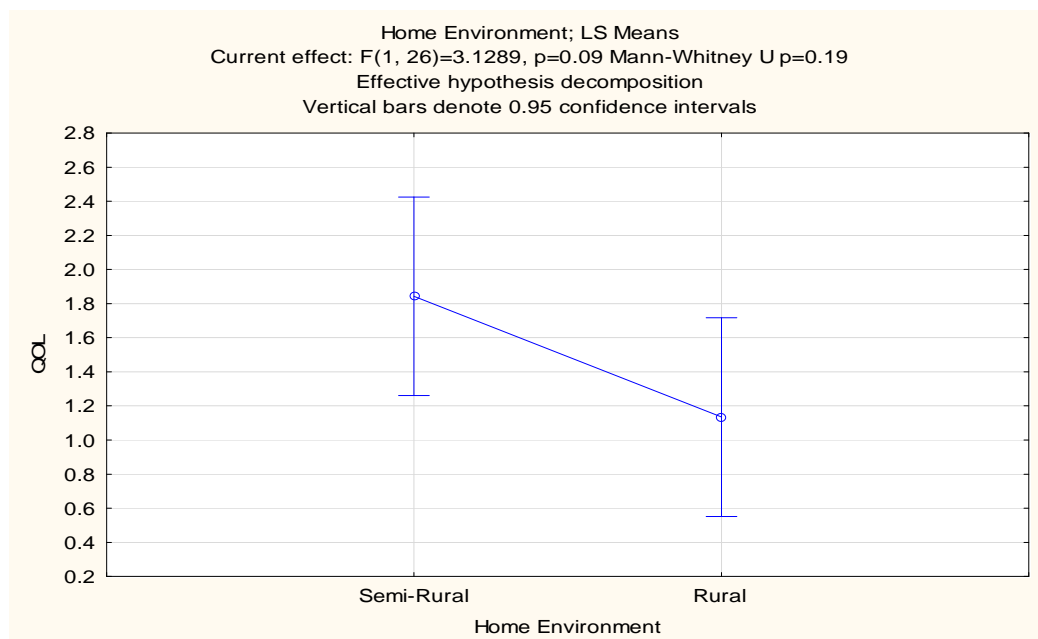
#### **4.1.6. Correlation between wheelchair satisfaction and wheelchairs issued**

Mann-Whitney U tests (Figure 4-13) show that there was no significant difference between participants living in rural and semi-rural areas regarding the psychosocial impact of the wheelchair on the participants' lives – the area where the participants live do not necessarily impact on their perceived QoL in the wheelchair.



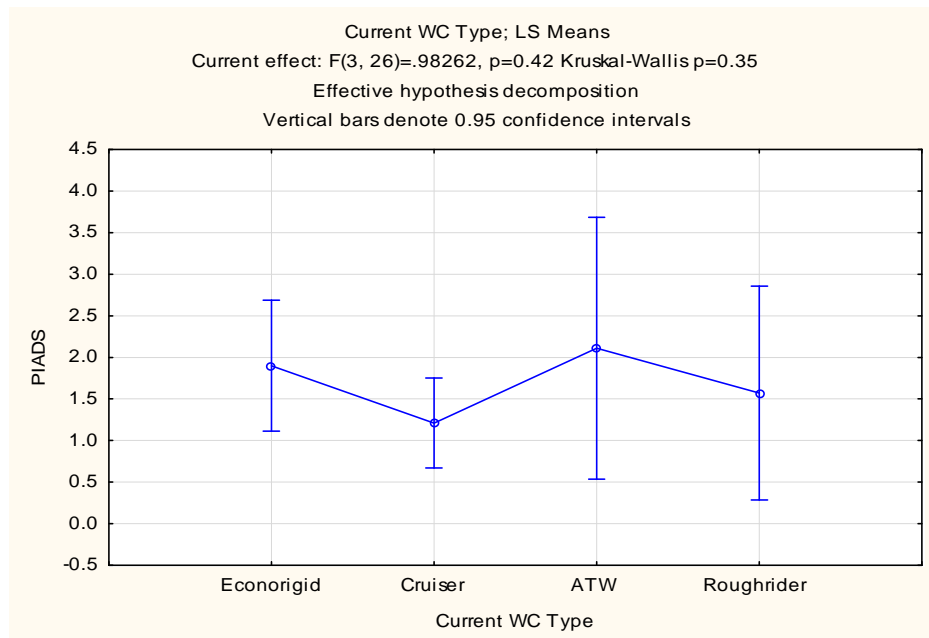
**Figure 4-13 Home Environment and PIADS**

Similar results were found with the QoL scores (Figure 4.14). No significant differences were found between rural and semi-rural settings ( $p = 0.19$ ). I.e. living environment (rural vs peri-urban settings) did not impact QoL in this sample.



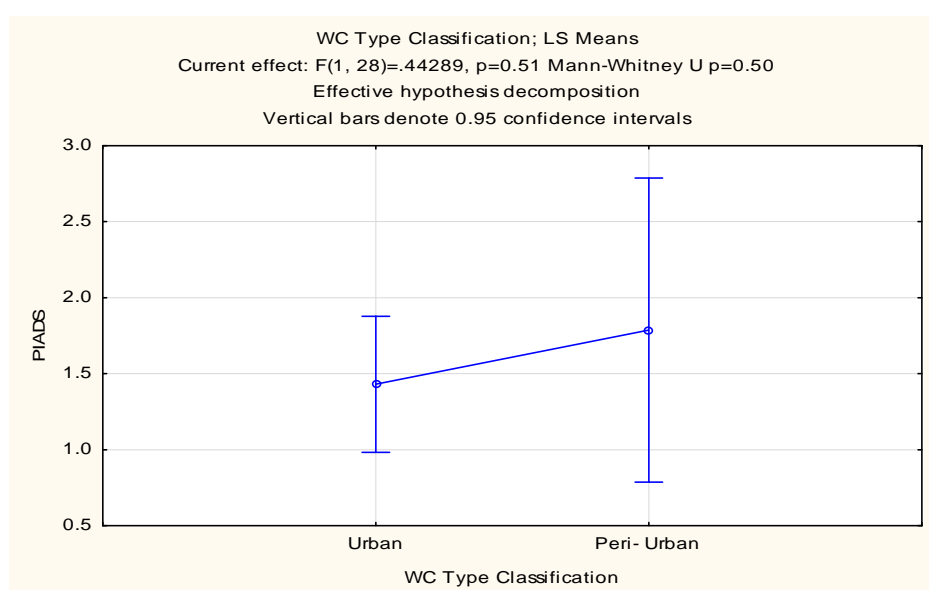
**Figure 4-14 Home Environment and QoL**

When the PIADS scores were compared to the current wheelchair type of the users, no significant difference was found (Figure 4.15) yet while not significant rural users scored lower in both instances (Figure 4.14 & Figure 4.15).



**Figure 4-15 PIADS and type of wheelchair**

Similarly, no significant difference was found between the wheelchair type classification and the PIADS scores (Figure 4.16). The Cruiser had the lowest average and the ATW had the highest average.



**Figure 4-16 PIADS and wheelchair type classification**

## 4.2 Phase 2

As previously described in chapter three, ten prescribing therapists participated in this phase of the study. Of the ten participants, nine had done the basic wheelchair course and four had done both the basic as well as the intermediate seating course. Only one participant had not done any of the specialised seating courses.

### 4.2.1 Therapist perception of wheelchair prescription

Table 4.15 displays the number of responses to the quantitative open- ended questions used in the semi-structured interviews with the prescribing therapists.

**Table 4-15 Number of responses to quantitative open- ended questions from semi structured interviews with prescribing therapists**

QUESTIONS	RESPONSES (N=10)
Know all wheelchairs on tender?	
Yes	6
No	4
Tender wheelchair prescribed most by participant in everyday practice?	
Cruiser	10
ATW	0
WM3	0
Econorigid	0
Roughrider	0
Pacer Lite	0
Should a wheelchair be appropriate and specific to every area of a client's life?	
Yes	8
No	2
Are the current wheelchairs on tender adequate to meet all the client's needs?	
Yes	3
No	7
Average time from prescription to delivery?	
< 18 months	0
18 months	4
> 18 months	6

<b>Challenges?</b>	
Time	10
Budget	9
Skills	4
Lack of home visits	6
<b>What should a wheelchair do for a client?</b>	
Foldable/Transportable	5
Ensure Mobility	4
Able to use in rural area	3
Lightweight	4
Easily adaptable	2
Comfortable	3
Postural Support	4
Facilitate social interaction	1
<b>What do clients want most out of their wheelchair?</b>	
Transportable	6
Manoeuvrable	4
Durable	1
Comfortable	3
<b>What do clients complain about most with regards their wheelchair?</b>	
Durability	5
Waiting list	3
Transport/ Accessibility	5
Discomfort	1

As seen in Table 4.15. all of the participants said that the standard folding frame wheelchair was the wheelchair that they prescribed most in everyday practice. Six (60%) participants knew all the wheelchairs on tender. Seven participants pointed out that they did not feel the current wheelchairs available on tender were adequate to meet all the clients' needs. One hundred percent of participants felt that the waiting list for wheelchairs were a big challenge.

From the responses to the open –ended questions asked during the interviews, the following themes were identified:

#### ***4.2.1.1 Perceptions related to Wheelchair Seating***

An open- ended question relating to how the participants felt about wheelchairs and seating was asked. Eight participants (80%) conveyed that they felt very positive about the effect of

wheelchairs and seating and that they believed it was both important and an integral part of rehabilitation of persons with disabilities. The following quotes support the above statements:

- “Passionate” (PT 9)
- “It’s important because it can increase or decrease mobility.” (PT 8)
- “It’s (wheelchair prescription) a critical aspect of rehabilitation and therapy and should be given more attention.” (PT 7)
- “..... very important to improve the client’s quality of life.” (PT 3)

Two participants however, felt that seating was not an interest of theirs. Both participants however still acknowledged the importance of seating.

- “It’s not a passion of mine although I realise there is a need for it. So even though I don’t enjoy it and I find it exhausting I choose to be a part of it because it helps patients.” (PT 5)
- “I’m not interested in it at all, but I know it is important.” (PT 6)

#### **4.2.1.2. Challenges as described by prescribing therapists**

The challenges reported by participants in some cases relate to each other and this will be discussed further in Chapter 5. These challenges described by participants included: poor funding, delayed delivery, inappropriate chairs available for environment and lack of therapists’ skills and training in terms of wheelchair prescription and seating.

##### **4.2.1.2.1 Funding**

Eight therapists reported insufficient funding to be a challenge (or barrier) to effective prescription practice. As a direct result of insufficient funding, the challenge of the waiting period was also mentioned by all of the participants. This resulted in therapists prescribing the cheaper chairs so that more patients would get access to a mobility aid in the form of a wheelchair. It also resulted in therapists issuing wheelchairs that no longer suited the clients at the time of delivery, as the waiting list is too long due to the funds not being available (by the time the wheelchair is issued, the client and their circumstances might have changed). The following quotes support therapist frustration at lack of funds:

- “Poor funding for wheelchairs makes it impossible to issue the correct wheelchair at the appropriate time because there is such a long waiting list.” (PT 3)

- “By the time you receive the wheelchair and issue it the prescription isn’t accurate anymore because the patient and their circumstances have changed.” (PT 6)
- “It’s a moral dilemma- something is better than nothing, so you end up issuing what you have available instead of what is most appropriate.” (PT 8)
- “The restricted budget is a massive problem. A letter of concern was submitted through the region’s Wheelchair Advisory Committee to the Rehabilitation Manager last year about this- no reply yet. We submit statistics on wheelchair orders every week to the CEO of our hospital, so that they are aware of the waiting list.” (PT 9)
- “I always think of the price before I order a wheelchair due to the budget constraints. I think before I order a specified wheelchair if it’s not life changing, because those wheelchairs are more difficult to recycle.” (PT 5)
- “Restricted to one wheelchair per client and one wheelchair can’t be appropriate to all areas of the client’s life.” (PT 3)
- “Long waiting list- a lot of patients pass away before they get their wheelchair. Funds are always a problem. Tender (suppliers) delivers when it suits them and this adds to the waiting period.” (PT 9)
- “Patients don’t get a wheelchair at the time of prescription, and two years later they probably need something completely different.” (PT 2)
- “Limited choice of wheelchairs available on tender.” (PT 10)
- “It shouldn’t be so difficult. We should be able to prescribe what the client needs of the tender and get it immediately.” (PT 4)
- “The patient needs a wheelchair so sometimes you need to give what you have available...” (PT 6)

#### **4.2.1.2.2 Training**

Some of the participants felt that lack of training and therefore the lack of the skills of the prescribing staff was a challenge/ barrier to prescribing the most appropriate wheelchair. The following quotes support therapist frustration with lack of training:

- “Yes, Cruisers are being ordered too often. It’s a habit we have gotten into because we don’t know other wheelchairs, especially the newly qualified staff – their experience start with Cruisers and then they get stuck.(I) might feel ATW/ other wheelchair is more appropriate but the client or the family want the Cruiser.” (PT 8)

- “Not enough product training from suppliers.” (PT 10)

#### **4.2.1.2.3 Wheelchairs available on tender**

Seven of the participants felt that the wheelchairs currently available on tender do not necessarily meet all the needs of the wheelchair users. The following quotes support this challenge/ barrier:

- “If you issue a rural wheelchair to the patient their house is too small for it and transport is a big problem.” (PT 2)
- “The wheelchairs on tender are good, but environment where the patient lives makes it very difficult to select a wheelchair. Access is a big problem and therefore patients often don’t want anything but a standard cruiser.” (PT 8)
- “The patient is very restricted in terms of transport – they want a folding wheelchair.” (PT 10)

#### **4.2.3. Therapists’ past experiences in wheelchair issuing**

Both positive and negative experiences relating to prescribing wheelchairs in the EC were reported by therapists.

##### **4.2.3.1 Positive Experiences**

The main themes seen from the positive experiences of prescribing therapists are as follows:

Three of the participants identified a positive experience of patients being happy with their wheelchair seating because they could feel it was better than the previous wheelchair or previous seating. They also related another positive experience as seeing clients at follow-up appointments doing much better than before (physically and psychologically) as a direct result of the wheelchair seating. The following quotes support these positive experiences:

- “Had a T12 spinal cord injury patient who was in a Cruiser and refused any other wheelchair. When we sorted his cushion out he said he could feel he was sitting better.” (PT 8)
- “Seeing patients come to their follow- up and they tell you that they actually feel better, and you can see that they look better.” (PT 4)
- “I’ve seen what a big difference the correct wheelchair can make.” (PT 10)



#### **4.2.3.2 Negative Experiences**

The negative past experiences of the participants far exceeded the positive experiences and have been themed as follows:

One participant mentioned the negative experience of issuing wheelchairs that had been prescribed by other therapists that were not appropriate for the wheelchair user and knowing that the patient would be “stuck” with that wheelchair due to budget constraints when patients were issued wrong wheelchair by previous therapist:

- “Wrong prescriptions by other therapists and then I had to issue the wheelchair, and I knew the patient was going to be stuck with that wheelchair. I couldn’t just order them something more appropriate because the budget doesn’t allow that.” (PT 8)

Two participants reported the negative experience of realising that a wheelchair they had prescribed was completely inappropriate prescription for the user upon doing a home visit for the first time (after having issued the wheelchair already):

- “I did a home visit and saw that the 20” wheelchair couldn’t get into the bathroom or fit through the doorframe.”(PT 5)
- “(I) issued a wheelchair to a tetraplegic patient, and when I did a home visit (I saw) the patient couldn’t move around inside his house with this big wheelchair because the house was too small.” (PT 7)

Two participants also mentioned the negative experience of seeing physical and postural complications caused by the wrong size wheelchair or inadequate postural supports because the lack of wheelchairs and the two year waiting period had forced you to issue an available wheelchair as opposed to waiting for an appropriate wheelchair:

- “In 2010 there was a gunshot wound patient who was put into a recliner wheelchair because it was all that was available. I saw how bad the wheelchair was for his posture and for his health. It was shocking.” (PT 2)
- “It’s always so sad to see young or active clients going home in cruisers because it’s the only wheelchair that is available at that time, sometimes it’s not even the right size!” (PT 10)

Lastly, one participant mentioned her experience of the high incidence of repairs due to terrain:

- “Seeing Cruisers/ standard folding frame wheelchairs being returned or brought in for repairs and realising that they are not good enough for the harsh environments clients live in” (PT 1)

### **4.3. Summary of results**

Wheelchair users in the EC are currently predominantly receiving standard folding frame type wheelchairs or cruisers more than any other type of wheelchair. These are generally perceived by users as sufficient to address their psychosocial needs in terms of mobility and transport, however these wheelchairs seem to fail users in terms of accessibility and independence within their rural and semi- rural environment.

Prescribing therapists in this study value appropriate seating, are knowledgeable regarding prescription practice and specification, but have voiced several barriers and limitations to this practice. These include budget restraints, time to delivery, lack of skills and training of prescribing therapists and inappropriateness of clients being issued only one wheelchair (due to budget restraints) to suit all aspects of life as well as the different terrains that the clients have to use.

Chapter 5 will discuss these findings in more detail.

# Chapter 5

## DISCUSSION

The findings of this study show that the wheelchairs issued to users through the Eastern Cape's (EC) Health Care system are generally perceived as sufficient to address their psychosocial needs in terms of mobility and transport. Wheelchair users are predominantly receiving the standard folding frame type wheelchairs or cruisers. These wheelchairs however seem to fail users in terms of accessibility and independence within their rural and semi-rural environment.

Prescribing therapists in the western region of the EC value appropriate seating, are knowledgeable regarding prescription practice and specification, but have voiced several barriers and limitations to this practice. These include budget restraints, time to delivery, lack of skills and training of prescribing therapists and the problem of clients being issued only one wheelchair (due to budget restraints) to suit all aspects of life as well as the different terrains that the clients have to use.

The following discussion elaborates on these findings.

### 5.1. Effect of sampling

Eastern Cape, the small sample of convenience selected for participation in the study seems representative of most wheelchair recipients in the broader EC in terms of type of wheelchair being issued based on provincial wheelchair database records. However, the small sample of convenience resulted in that wheelchair users in rural areas situated far from any health centre were excluded and their input could have added greatly to this study. The female to male gender ratio of wheelchair users also seem representative of wheelchair users' worldwide (Paquet & Feathers, 2004). This may be explained in that the majority of the current sample had suffered a spinal cord injury (43%), and according to the literature males tend to suffer from spinal cord injuries more often than females (Dryden, Saunderson, Rowe, May, Yiamakoulis, Svenson, Schlopflocher & Voaklander; 2003). Similarly the mean age of participants was 43.3 years, which also seem representative of wheelchair users worldwide (Paquet & Feathers, 2004; Furlong & Connor, 2007).

## 5.2. Wheelchairs issued in the study setting

Participants were prescribed various chairs, some with cushions, and some without. Not all participants were issued a chair appropriate to match specifications. This and the implications thereof are discussed in more detail below.

### 5.2.1 *Type of wheelchairs issued*

Just over half of the study participants were issued with a CE Cruiser® while a further 27% used an Econorigid wheelchair. Both these wheelchairs can be classified as urban mobility assistive devices (PGWC DoH, 2009b). The Cruiser is suitable for low active clients, while the Econorigid is considered appropriate for active wheelchair users. Both are compact for indoor use. The adjustable wheelbase of the Econorigid allows for the front castors of this wheelchair to have minimum weight over them which in turn add to the manoeuvrability of the wheelchair. The adjustable settings on these wheelchairs optimise access to the rear wheels which influences the effectiveness of propulsion. It is the experience of the principle investigator (PI) that for many active/ young clients, this has been found to be the wheelchair of choice on the national tender due to its lighter weight and transportability. Although this wheelchair does not fold up, the backrest folds onto the seat and the rear wheels are easily removed with the quick-release mechanism (PGWC DoH, 2009a; PGWC DoH, 2009b). Many of the participants in this study sustained incomplete spinal cord injuries (SCI). These users often fit into the category of both young and active (Dryden, Saunderson, Rowe, May, Yiamakoulis, Svenson, Schlopflocher & Voaklander; 2003). The Econorigid wheelchair is however not suitable for either rural or semi- rural environments, because of the thin rear wheels and front castors, the low position of the footplate in relation to the ground (making it hard to clear uneven terrain) and the short wheelbase making the wheelchair too unstable for uneven terrain (PGWC DoH, 2009a). Despite this, many users living in a semi- rural environment were satisfied with this device due to the wheelchair's lighter weight and centre of mass (COM) settings enabling the users to be highly active. Many were also using these wheelchairs for sport such as wheelchair basketball. One qualitative study revealed that professional wheelchair sportsmen and –women considered stability to be the most important contributing factor towards performance, and this is a factor that the Econorigid wheelchair offers (Mason, Porcellato, van der Woude & Goosey-Tolfrey, 2010; PGWC DoH, 2009b). The results, even though not statistically significant, show that the users of the Econorigid had on average better functional, safety and quality scores.

In the present study, three users had suffered a cerebro-vascular accident and all three of these users were over the age of 60. Both these factors – diagnosis and age - are associated with a low-active client (Steffen, Hacker & Mollinger, 2002). All three of these clients were issued with a Cruiser, an appropriate assistive mobility device for their everyday functioning.

The diagnoses resulting in the need for a device to assist with mobility for most participants in the current study were SCIs. This was followed by persons with osteogenesis imperfecta, polio and amputations - all of whom are likely to function at high levels of activity, and thereby ‘entitled’ to a more appropriate active wheelchair that suits a rural/ semi- rural environment (PGWC DoH, 2009a). The mean age of these participants was 43.3 years also a criterion associated with increased levels of functional ability and activity levels. A more appropriate wheelchair may have allowed for better independent functioning. However this would still need to be tested empirically.

Three participants were using a Roughrider® and the remaining two participants were using an all-terrain wheelchair (ATW®). These two wheelchairs are classified as semi- rural/ peri-urban wheelchairs. The adjustable longer wheelbase of the ATW allows for the front castors to have minimum weight. According to the wheelchair database of the Western Region of the EC, there has been a recent increase in the prescriptions of Roughrider wheelchairs, possibly due to product training. The Roughrider wheelchair (PGWC DoH, 2009b) is the only foldable semi- rural wheelchair with four wheels, making it look more like the ‘traditional’ wheelchair. As seen in the results (e.g. Figure 4.15), these wheelchairs and specifically the ATW always had the highest high score as well as the biggest range of scores. Therefore it is the opinion of the PI that these chairs can significantly improve a person’s function and quality of life, but can also have a negative impact, possibly as it relates to small house environments and transporting these bulkier chairs. These chairs should therefore always be prescribed after conducting a home visit. A home visit however will only provide the prescribing therapist with insight into whether or not the wheelchair can be used inside the home. To effectively assess whether the wheelchair is suitable for the client’s life the therapist should ideally see other places within the client’s community life that the client needs to visit. This may assist in choosing the correct singular wheelchair.

From earlier database audits it can be seen that the Cruiser is the wheelchair of choice for both therapists and clients in the EC, while this may have been attributable to the fact that the Cruiser was the only wheelchair available on tender up until 2000, this phenomena has not

changed even with therapists now having more than six wheelchair types to choose from (DoH, 2003).

Therapists however acknowledged that the Cruiser may not be suitable for the harsh environments that many of our clients live in, as their wheelchairs were regularly being brought in for repairs. Poor funding restricts users to one wheelchair only as there are not enough funds to issue more than one wheelchair to a user. This makes it very difficult to choose the correct singular wheelchair appropriate for both confined indoor as well as rough outdoor terrain. As mentioned before, although the patient is from a rural/ semi- rural environment and therefore ideally needs a rural/ semi- rural wheelchair for optimal outdoor mobility, the users prefer a foldable more compact wheelchair design as their inside living space and transport requirements dictates this design.

It is perturbing that none of the participants living in a rural setting were issued a World Made 3®(WM3) (the only rural wheelchair currently available on tender (DoH, 2003). This is possibly due to the users' perception of the overall size of the wheelchair (longer than standard length) as well as the difficulty to transport the wheelchair (three- wheel design, rigid back, not foldable (PGWC DoH, 2009b). These factors could influence both therapists and clients to be less inclined to order this wheelchair.

Only eight participants were using a wheelchair that suited all aspects of their environments (i.e. indoors and outdoors) however the majority (n=17) of participants were using a wheelchair that suited at least one aspect of their environment. Four-wheeler wheelchair designs are less effective on uneven terrain as it needs four points of contact for traction and stability (PGWC DoH, 2009b). Four-wheel wheelchairs often get stuck on uneven terrain when one rear wheel loses contact and traction – thus negatively impacting the user's independence, safety and quality of functioning every day with a wheelchair in rural/ semi-rural areas. Three-wheeler designs however are specifically designed for rough terrain and will at any time have all three wheels on the ground for optimal propulsion and traction (PGWC DoH, 2009b).

The design of a low-active urban wheelchair, like the Cruiser, does not include different centre of mass (COM) settings which allows for safer and higher quality mobilisation outdoors. The foldable design also makes the wheelchair more unstable when mobilising outdoors, compared to a rigid non- foldable design. However, all of the participants lived

either in a small house or a shack. To use a three- wheel design wheelchair (such as the WM3) inside such small spaces is impractical, as these wheelchairs have both a long wheelbase and a large turn- circle. Therefore many clients prefer a smaller, foldable type wheelchair. The findings of the current study support the rationale that many wheelchair users should have two wheelchairs (one for indoor use and one for outdoor use) (PGWC DoH, 2009b).

### **5.2.2 Wheelchair fit**

Thirteen participants (43%) were using an incorrectly sized wheelchair for current anthropometric measurements. The size of the wheelchair will affect the user's fit and therefore postural support as well, as the correct size prevents the pelvis from shifting laterally or moving into an obliquity. Therefore a wheelchair that is either too large or too small may significantly impact on independence, safety and quality of mobility and functional activities in the wheelchair, and may lead to secondary complications such as windswept deformities or scoliosis (PGWC DoH, 2009a). Independence will be impacted in that the users will most likely need assistance with functional activities such as transfers as the overall stability of the user is compromised (PGWC DoH, 2009a). The size will also affect the user's access to the rear wheels for propulsion - requiring assistance, as well as access to small indoor environments - resulting in exclusion and restricting participation (Brickenbach et al., 1999; WHO, 2011; Chaves, Boninger, Cooper, Fitzgerald, Grey & Cooper, 2004).

One of the participating therapists described a negative experience of being forced to issue a young patient with a spinal cord injury a Cruiser that was not the correct size, as it was the only wheelchair available at the time and she did not want the patient to be discharged home without a mobility device (This patient did not form part of the current study sample and therefore his/ her satisfaction and function in the wheelchair was not assessed).

The current study also assessed the overall biomechanics of the user in the wheelchair in order to determine whether biomechanical principles of seating had been incorporated, including stabilization of the pelvis and of the spine in the seated posture. As all deviations in pelvic alignment translate to the spine and will impact on postural alignment and function it is recommended that seating should start by focusing on the pelvis (PGWC DoH, 2009a). The pelvis is stabilised in the wheelchair by ensuring that the cushion is adapted according to

the user's body measurements (position of the ischial tuberosities) and as mentioned before, by ensuring the correct seat width for the user. Furthermore the pelvis is stabilised posteriorly by providing a posterior force at the level of the posterior superior iliac spine (PSIS). This force is best provided with a backrest that has adjustable contouring settings (e.g. tension adjustable, rigid adjustable or modular back system) (PGWC DoH, 2009a).

The spine is supported and stabilised by supporting the lumbar lordosis with the use of an adjustable backrest and lumbar support (if required). Furthermore, the natural curvature of the spine needs to be accommodated or supported- the backrest system should be able to open up to accommodate the thoracic kyphosis (PGWC DoH, 2009a).

In the current study only five participants had a perfect anthropometric fit (refer to Chapter 4.1.2). This is possibly due to the fact that very few of the users were using a wheelchair with an adjustable back system – even though they needed such a back system. Similarly despite the Econorigid coming standard with an adjustable back, most participants' back systems had not been adjusted at all according to their back curvatures. It is presumed that participants failed to go for their seating follow-up dates (a tension adjustable back needs to be re-adjusted regularly) most likely due to transport and financial difficulties. Furthermore the wheelchair cushions of the users had in many cases not been adjusted at all and as mentioned before in some cases were missing.

### **5.2.3. Wheelchair cushions**

More than two thirds of participants were using a wheelchair cushion at the time of the study and 23% of participants reported a present or previous pressure sore and five had cushions not adequately adapted to suit their body build in order to assist with pressure relief. Although the number of participants who reported that they either had a history of pressure sores or currently had a pressure sore equalled the number of participants who were not using a wheelchair cushion, there was no correlation between the occurrence of pressure sores and no cushion. A systematic review by Reddy, Gill & Rochon (2006) revealed similar findings. Four randomised control trials relating to the effectiveness of wheelchair cushions were reviewed, and the incidence of pressure sores were no different in the intervention groups. However, evidence does also show that when a wheelchair cushion is adapted according to the user's biomechanical measurements, there is significant pressure redistribution away from the critical pressure areas and that this redistribution of pressure aids in the prevention of



pressure ulcers (Brienza, Karg, Geyer, Kelsey & Trefler, 2001). An efficient wheelchair cushion should reduce the level of pressure by distributing pressure away from critical areas (like the ischial tuberosities and the sacrum) and by distributing pressure over a larger contact area (Eitzen, 2004).

In the current study, the wheelchair cushions of five participants had not been adequately adapted to suit their body build. All wheelchair users should be prescribed a wheelchair cushion to assist in the prevention of pressure ulcers. This is supported by the DoH (PGWC DoH, 2009a). The only cushions however currently available on tender are a thin positioner and a thick pressure care cushion and the results of this study suggest further research into this area. Similarly government should consider making available a larger variety of cushions on tender.

### **5.3 Wheelchair usage**

Ninety per cent of the wheelchair users in the current study had been using their wheelchair for more than one year and all participants used their wheelchair daily. Just over half spend more than 6 hours in their wheelchairs daily. No participants in this study have completely abandoned their wheelchairs. Some of the wheelchair users mentioned that they are aware of the waiting list and the probability that they would wait a very long time for another wheelchair, and it is the opinion of the PI that this may be why none of the users in the current study had completely abandoned their wheelchairs. Literature however shows that even in low resourced settings wheelchairs are abandoned if they are inappropriate according to the users (Mukherjee & Samanta, 2005). Although not appropriate for all users, none of the current sample had abandoned their wheelchair suggesting that in their setting any chair is still better than no chair. While this may not seem problematic in this group of participants, spending so much time in an inappropriate device can be harmful to the participant's health as well as detrimental to their future function and independence (Fogelberg et al., 2009).

Most of the participants living in a rural or a semi-rural environment used a hired car as transport as they felt that their current wheelchair did not allow them to use public transport safely, independently or effectively. Many participants reported that the taxis would not stop for them, apparently because it took so much longer for a wheelchair user to transfer into the taxi and load their wheelchair in compared to an able-bodied client. This subsequently has financial (time) implications for the taxi owner. When asked about using a bus, the users

reported that they need help to get into and out of a bus as these vehicles are too high to transfer independently, in which case a family member or friend was needed. Thus the only option for independent transport was a private car hire, which has great financial implications for the users.

#### **5.4 Home visit by a therapist**

Only two of the participants had ever had a home visit by the prescribing therapist. It has been seen that home visits are crucial to ordering the most appropriate wheelchair as the home environment of the client dictates the type of wheelchair (Reid, 2002; PGWC DoH, 2009a). Therapists participating in the current study reported many barriers to being able to conduct home visits, including transport problems due to budget constraints and shortage of staff. Therapists who have conducted home visits also mentioned a negative experience of only realising during a home visit that the wheelchair they had issued was inappropriate for the user, even though they had asked the user what their home environment is like prior to prescribing the wheelchair. Therefore it is the opinion of the PI that to subjectively assess the user's home environment should by no means replace conducting home visits in order to appropriately prescribe and issue wheelchairs.

#### **5.5 Challenges to wheelchair prescription**

Therapists reported many challenges when prescribing wheelchairs. One challenge that many therapists reported was the lack of training from the suppliers and/ or other skilled parties to prescribing personnel. Basic knowledge of the wheelchairs available for prescription is vital in order to prescribe and issue the best possible wheelchair. Although all but one of the participating therapists had completed the Basic Seating Course only six therapists were able to name all the wheelchairs currently available on tender. However, all knew that the World Made 3 (WM3) – a chair which should have been most often prescribed given the geographical area these therapists serves - was available on tender. This was most likely due to the nationwide training by the issuing company informing all therapists of its availability and advantages for patients in rural settings.

Another challenge reported by therapists is lack of experience. Many participating therapists mentioned that because they didn't seat clients often, it was always a challenge when a client needed to be seated. As seating is a specialised field that requires skill and experience, on-going training is vital to ensure that high standards are maintained in this area.

A third challenge reported by therapists is budget constraints. Ordering rural/ semi- rural devices is more expensive than ordering a Cruiser, which would deplete the budget available for wheelchairs faster. At most of the institutions, participants mentioned that the limited budget available for wheelchairs forced them to issue what is currently available so that more patients would be assured a wheelchair. Although it might assist access to a wheelchair sooner than what the waiting list allows, the wheelchair issued may not be specific to meet the needs of the user. This practice does not align with the WHO service delivery steps or the SA national guidelines (WHO, 2008; DoH, 2003). However, for a client that is not able to mobilise any other way than with a wheelchair such as a patient who has suffered a spinal cord injury or bilateral amputations, it is understandable why therapists would at times issue what is available instead of wait for the appropriate device. In some instances it has been reported to take as long as 18 months to two years. Currently in this region, there is also no short term solution for this such as hospital loan chairs. The WHO advises in such cases that the wheelchair being issued be as close as possible to what the user requires (WHO, 2008).

In the current setting clients may however also have contributed to this problem of issuing the folding type chair or Cruiser. One therapist reported that one of her clients disliked the size and look of the other wheelchairs and preferred the standard Cruiser as it is culturally more aesthetically acceptable. This wheelchair is both small and transportable, which means it can both fit into a small dwelling and be put into a taxi if the client needs to go somewhere and therefore the preferred option for an assistive mobility device. Another reason reported by therapists for issuing predominantly the one type of wheelchair is due to the ‘convenient habit’ (sic) of ordering standard folding frame/ Cruiser type wheelchair.

Half of the therapists felt that the wheelchairs currently available on tender were not able to address all aspects of clients’ lives. However some of the participants did mention that were the users able to go home with more than one wheelchair (one for inside use and one for outside use) the wheelchairs currently on tender would in their opinion be adequate.

## **5.6 User’s level of satisfaction with the wheelchair**

As 90% of the wheelchair users had been using their wheelchair for more than one year (47% more than 5 years), the assumption was made that most of the participants had enough experience in their current wheelchair to know what they liked and what they disliked about their wheelchair.

Only one of the participants reported that their current wheelchair did not allow him/her to transfer safely, independently or effectively, while objective measurement found that seven participants needed physical assistance in order to do a safe and effective transfer from the wheelchair to the plinth or bed. This discrepancy in the 'Transfer' item scores between what the users rated they were able to do and what the PI found was because the PI had to correct the position of the wheelchair in relation to the bed/ plinth many times in order to ensure a safe transfer. This automatically demoted the independence scores. Another aspect that lowered the independence scores for this item was the fact that many of the wheelchairs brakes were either faulty or missing, in which case the PI had to physically assist by holding the wheelchair to ensure a safe transfer. Similarly the safety scores for this item were also low (refer to Chapter 4.1.3), as a safe transfer is impossible with faulty brakes. This could once again be due to lack of user training by therapists. Standard wheelchair issuing procedure within the Western Region of the EC however states that upon issue each user must be made aware that the wheelchair needs to be serviced at a repair centre every three months. On the other hand, some users may even be aware of this but unable to travel to a repair centre due to the transport difficulties as have been discussed above.

Another item that obtained low safety and quality scores was the self-operation of the wheelchair. This included locking and unlocking the brakes of the wheelchair. Many wheelchairs in the current study either had no brakes, only one brake or faulty brakes. As effective brakes are such an integral part of safety for the wheelchair users, failing to do this part of the task automatically decreased the safety score as well as the quality scores as this would mean that the standards were not met for this item.

Outdoor mobility and transport were the two aspects of wheelchair functioning that were reported by users are most problematic. More than half (57%) of participants were unable to manoeuvre up and down an inclined easy terrain, propel their wheelchair over both a flat easy and a flat difficult terrain or move up and down a curb/ sidewalk move outdoors. With regards to the safety with which the users mobilised outdoors, most of the safety issues arose with mobilising up and down a curb/ sidewalk as most users had to be assisted with this task to avoid harm to the users. Some of the users were able to mobilise down the curb with good quality sequence of movements but not up again.

It is the assumption of the researcher that a more appropriate wheelchair would have allowed selected participants a higher level of functioning.

Mounting curbs was another limitation identified in the current study. The design of the Cruiser (loaded front castors) makes it difficult to wheelie up a curb, as the front castors are loaded too much. Many participants mentioned however that they had never been trained to wheelie up/ down a curb and the ones who were able to do this complex task related that they had either taught themselves or had learnt from peers. The researcher was unable to confirm this with their prescribing therapists.

Transferring into the vehicle and folding and loading the wheelchair into the vehicle independently was reported by all but four participants. This could be due to the fact that most of these participants always had a friend or family member accompany them on outings and the wheelchair was stowed by the caregiver and not by the wheelchair user. One of the reasons that only four users were able to do this independently may be the lack of dexterity training done by therapists - all participants who failed this task also related that they had never been shown how to do this. Incorrect wheelchair size could also negatively impact this function as stability and posture is influenced by the size of the wheelchair. No correlations were however found between these two aspects.

The seemingly low safety scores awarded to the item Comfort Needs in contrast with the high scores awarded by the users themselves, relates to the safety with which the participants were able to improve their comfort within the wheelchair. This has a direct influence on the safety of the user's overall health and subsequently on item 2: Health Needs (refer to Chapter 4.1.2), as an ineffective or unsafe pressure relief technique increases the risk of pressure sores. Again, these ineffective pressure relief techniques are most likely due to lack of training from the therapists- this would however need to be assessed further.

Wheelchair users in this study felt quite satisfied with the functions their wheelchairs enabled them to do overall. One of the reasons they rated their wheelchair functioning as high may be because the items on the outcome measure used – the FMA (refer to Chapter 3.6.1) are phrased quite broadly (e.g. “My current wheelchair allows me transfer independently, safely and effectively.”) and does not reveal the complexity of the task (for example transfer to different surface heights safely without any help). When each of these items were thus tested more objectively, many other issues were seen with the independence, safety and quality of each task, that might have seemed unimportant to the participants.

## **5.7 Psychosocial impact of wheelchairs on users**

Competence, adaptability and self-esteem are important psychosocial factors that typically are not taken into consideration when evaluating wheelchair functioning. Studies that have investigated abandonment of wheelchairs often report that embarrassment, frustration, loss of independence and inability to participate in community activities are just some of the emotional aspects affecting persons living with wheelchairs (Scherer & Cushman, 2001; Kittel, DiMarco & Stewart, 2002; Day & Jutai, 1996). Participants in the current study reported relative satisfaction with their wheelchairs and that they were able to adapt and established ways of coping with the changes that accompany disability (Day & Jutai, 1996). This could possibly be linked to the fact that almost half of the participants (n=14) had been wheelchair bound for more than 5 years and had therefore spent enough time within their wheelchairs to adapt to the many challenges that accompany disability.

Participants however reported that despite satisfied with the way their wheelchairs assisted them in doing activities of daily living and making them more willing to try new things they still reported a high level of embarrassment stating that the wheelchair in fact made them feel more embarrassed. This and the overall low mean of the subscale Self- Esteem could possibly be due to cultural belief systems- where disability as seen as a deviation from what is normal and people with disabilities are looked down on by society, as seen in the medical approach to disability (DPSA, 2004; Mackelprang, 2010).

Despite the high level of satisfaction reported by all the users in this study, users in semi-rural wheelchairs were able to function significantly better than those not in semi-rural wheelchairs. It has been seen in similar research worldwide into user satisfaction with assistive technology using a number of different outcome measures, that users do in fact report higher levels of satisfaction than what is seen functionally and what is anticipated (Wessels et al., 1998; Brandt & Iwarsson, 2001; Benedict et al., 1999; Weiss- Lambrou et al., 1999; Bursick et al., 2000; Routhier et al., 2001; Vincent & Demers, 2002).

## **5.8. Correlation between self-reported functioning and wheelchair specification**

The findings of this study showed that the wheelchair impaired overall function in approximately one third of users, and that 40 % of participants were currently using a wheelchair that facilitated their overall function. Function within a wheelchair can be

affected by many things including: Overall length, type and size of the wheelchair, seat height, arm- and footrests, weight of the wheelchair, transportability, access to the rear wheel, rear wheel camber, user skill and ability and stability versus mobility (centre of mass). Length and type of wheelchair (i.e. rural 3- wheel design with longer wheelbase) are especially important when considering the function of the user indoors; such as access to cupboards and transfers (PGWC DoH, 2009a). Seat height can affect function as a seat that is too high restricts access under tables/ desks and can affect stability (related to COM). A seat that is too low on the other hand, requires lower footplates which may catch on uneven terrain or when mobilising up or down a curb/ ramp. Correct set-up of the wheelchair and unloading of the front castors (ensuring that the COM of the user is over the rear wheels) will improve the ability of the user to clear the front castors (i.e. on rural terrain, curbs) and thus enhance both manoeuvrability and safety.

The WHO Guidelines for the Provision of Manual Wheelchairs in Less Resourced Settings states, amongst other considerations, that “a wheelchair is appropriate when it... provides proper fit and postural supports.” This however was not found in this study with more than two thirds of the current sample scoring < 3 (optimal score) and eight users scoring 0 - meaning the chair offered no postural support at all for example the tension adjustable back (TAB) had not been adjusted at all, wheelchair cushions were missing and rigid back systems had not been prescribed as necessary. According to the literature correct positioning and posture may prevent spinal deviations, prevent pressure sores, enhance function in the wheelchair, provide comfort and enhance aesthetics and self- image (PGWC DoH, 2009a). This study suggests that more attention to cushioning and inserts need to be considered by therapists when prescribing a wheelchair. The following wheelchair components and factors need to be considered when selecting an appropriate wheelchair to optimise postural support: seat width, seat depth, footrest height, cushion design, backrest, armrests and tilt in space (PGWC DoH, 2009a).

One third of the users received the optimal score relating to whether or not their wheelchair adequately supported their posture (refer to Chapter 4.1.4). This could possibly be related to the finding in the WSC Part A, which revealed that 23% of the participants were not using a wheelchair cushion at all – an integral part of postural support within a wheelchair. Again, inappropriate wheelchair size has an influence as the correct width prevents pelvic obliquity

and lateral shift and the correct seat depth prevents slumping in the seat, pressure in the popliteal area/ back of calves and poor stability within the wheelchair.

Therapists are aware that correct or better seating can significantly improve posture and level of functioning in their clients and that more time and effort when prescribing wheelchairs and appropriate postural supports can enhance the user's perceived quality of life.

## **5.9. Summary**

There are many issues and challenges regarding wheelchairs and seating in the EC. Various wheelchairs are being issued to patients in the WRoEC, however the Cruiser is prescribed more often for reasons predominantly emanating from budget constraints and aesthetics. Generally wheelchair users are satisfied with their standard issue Cruiser wheelchair although those living in a semi-rural or rural environment did report problems with outdoor mobility and those with semi-rural wheelchairs identified problems with transport due to the overall size of the wheelchair. More appropriate wheelchair design and on-going training for prescribing therapists is recommended. The long term effect on health and cost of sitting in inappropriate chairs still needs to be investigated in this population.

The study however had several limitations which will be discussed in the next chapter. Chapter 6 will also provide the recommendations for future research emanating from this study.



## Chapter 6

A descriptive observational and correlational study was used to describe current wheelchair prescription practice in the Western Region of the Eastern Cape (WRoEC), and to determine whether the wheelchairs that are currently being issued address the psychosocial needs of persons with disabilities living in the Eastern Cape (EC). Due to time and budget restraints the study made use of convenience sampling and as such has some limitations and generalizability is restricted to the Western Region of the EC. These are discussed in more detail below. This chapter is a summary of the major findings. Recommendations for further research as well as for clinical practice are also described.

### 6.1 Conclusion

Therapists in the WRoEC are predominantly prescribing the standard folding frame wheelchair more than any other type of wheelchair, in some instances regardless of the home environment of the patient and awareness of the variety of chair available on tender. The manoeuvrability and transportability features of the Cruiser were reported by therapists as the main reason for this with patients often requesting this type of wheelchair from the therapists. In addition, therapists often felt they had no choice in issuing another chair due to budget restraints and - as a direct effect of this - the long waiting period for wheelchairs. Lack of skills training was also sighted as a reason for the high incidence of what may be inappropriate wheelchair prescription.

Wheelchair recipients in the WRoEC living in semi-rural and rural living environments are currently being issued chairs that do not meet the requirements for outdoor mobility and transport- although participants were quite satisfied with these wheelchairs, room for improvement was seen in most of the functional tests conducted in these chairs.

Another issue that became apparent as a result of the poor funding, was the lack of home visits being done by issuing therapist- as therapists mentioned that they often only realised the wheelchair was inappropriate upon conducting a home visit long after they had issued the wheelchair when funds became available.

## **6.2 Limitations of the study**

In this study, the principal researcher (PI) attempted to collect data in as structured a manner as possible with the aim of providing clinically relevant information. Certain shortcomings however, were experienced and must be taken into consideration when interpreting the data, and should be addressed in future studies.

### **6.2.1 Sampling**

Because the sample size of the current study was limited due to time and financial restraints, the external validity of the study was compromised. Sampling was based on the current home address of the user (rural/ semi-rural) and the amount of time the user had been in the wheelchair. The findings can therefore only be generalised to the WRoEC. Furthermore, because convenience sampling was done and users closest to the PI were invited to take part, many issues that specifically relate to wheelchair users who live far from health services could have been missed. Despite the volume of data collated, the small sample size did not allow for extensive sub-group analysis to explore relationships between variables - for example it was not possible to determine whether the type of wheelchair cushion issued correlated with the pressure sores reported by wheelchair participants. Similarly very few correlations could be made between the type of wheelchair and many of the other analyses such as independence, safety and quality of movement and function in the wheelchair.

Furthermore, compiling an implementation model was not possible as information of users in urban settings was not collected, and because the rural setting in this study was limited to the borders of the town that the PI lives in therefore deeper rural environmental issues and user needs may have been missed.

### **6.2.2 Outcome measures (OM) used:**

A range of outcome measures were implemented in this study in order to reach the different objectives in the most accurate and comprehensive way possible. A potential bias was thus avoided by assessing the appropriateness of the wheelchair in as holistic manner as possible.

All data was collected by the principal investigator for Phase 1 and Phase 2 of the study. Although this could have resulted in potential measurement bias, considerable effort was taken to ensure standardised measurement procedures – verbal input during the

administration of the FEW was standardised and the same trained assistant and translator was used for all participants. For each home visit, the PI considered the living space and environment upon arrival so as to find the best possible areas in which to conduct the different items of the FEW-P, to further ensure standardised measurement procedures. Although this was obviously different for each home visit participant, the FEW-P was specifically designed to be used within a client's home environment and to be used interchangeably to the FEW-C.

The FMA was used to determine the users' level of satisfaction with the wheelchair. This scale was filled in before any of the more objective testing (FEW-C/ FEW-P, WSC-B) was done, so it is possible that the participants thought they could do a lot more within their current wheelchairs than what was later observed. Also, the FMA scale is only available in English and although an interpreter was available, translation error remains a possibility.

## **6.3 Recommendations**

Several recommendations for further research and for clinical practice have emerged from this study:

### ***6.3.1 Recommendations for future research***

A larger sample size is recommended for similar research to allow for subgroup analysis and possible regression analysis to help determine factors predictive of good outcome and provide greater insight into associative factors. Multi-centre studies to get more accurate statistics of problems experienced nationwide would increase generalizability of study findings to more wheelchair users and assist in improving planning of tender services as well as clinical practice. It would also be valuable to see whether or not urban wheelchair users face the same challenges as rural/ semi- rural wheelchair users, as it can not be assumed that they do not. The current study however was restricted to rural and semi- rural environments.

Translation of the FMA questionnaire into isiXhosa and Afrikaans so as to rule out miscommunication is recommended. Furthermore, an OM to assess user's function within their home environment that is specific to the rural/ semi-rural environments of South Africa would add great value to future research in this area.

### **6.3.2 Recommendations for clinical practice**

The need for more than one wheelchair per patient (or a more versatile wheelchair design) was clearly seen in this study and should also be considered for future research in this field. The type and more specifically size of housing within the rural and semi-rural environments of study participants makes it very difficult to use a rural/ semi-rural wheelchair inside the house, as these wheelchairs are in most cases bigger and less compact. Current advances in mobility technology (such as all terrain vehicles) should also be incorporated into wheelchair designs for the rural terrain our clients live in.

Were there a bigger budget for wheelchairs in the Eastern Cape, the issue of the long waiting list could be addressed. Earlier and more appropriate access to wheelchairs will most likely address the psychosocial needs more closely for wheelchair users living in semi-rural and rural environments.

Service providers and managers must be educated on the importance of following the WHO Guidelines regarding wheelchair prescriptions, and especially that of conducting home visits prior to ordering wheelchairs. The opportunity to conduct timely home visits to need to be implemented. It is clearly evident from the literature and from the results of this study that home visits are important to correctly prescribe wheelchairs for persons with mobility challenges.

Furthermore, on-going training is recommended in order to minimise the habitual practice of issuing Cruisers. On-going training will ensure that therapists remain up to date with current availability of chairs as well as when and in which settings to issue these chairs, so that when new products do become available they are promoted effectively.

The need for user training was also identified in this study. This needs to be implemented, not only from professionals but possibly also from peers. Some of the wheelchair users in the current study relayed that a lot of the more complex functional skills they were able to do, they had learnt from peers, indicating towards the value of peer training in accordance with literature.

Many of the barriers identified during this study do not only relate to an appropriate wheelchair. An integrated approach by many different parties is clearly needed within the

WROEC, including transport, housing and social services. This will effectively ensure that the psychosocial needs of PWD's within this region are addressed holistically.

The results of the current study show that wheelchair prescription in the Western Region of the Eastern Cape is restricted. Although the wheelchair participants were for the most part satisfied with their function and abilities in their current wheelchairs, this study has identified many areas for improvement in the users' overall functioning, postural support and biomechanics within their wheelchairs, especially as it relates to their home environment. There is much scope for improvement of delivery of wheelchairs to persons with disabilities in the WROEC – from on-going education and training of therapists and clients to more appropriate wheelchair design for persons living in rural settings. Further research in this field is recommended.

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<http://www.doh.gov.za/tenders.php?type=Tenders>

# **APPENDIX 1:**

## **PIADS**

# Psychosocial Impact of Assistive Devices Scale (PIADS)

Today's Date(MM/DD/YYYY)

 /  / 

Client Last Name

☐ male ☐ female

Client First Name

Date of Birth(MM/DD/YYYY)

 /  / 

Office Use only - ID#

The form is being filled out at (choose one)

☐ home

☐ a clinic

☐ Other(describe):

The form is being filled out by (choose one)

☐ the client, without any help

☐ the client, with help from the caregiver (e.g., client showed or told what answers to give)

☐ Other(describe): 
☐ the caregiver on behalf of the client, without any direction from the client

Each word or phrase below describes how using an assistive device may affect the user. Some might seem unusual but it is important that you answer every one of the 26 items. So, for each word or phrase, put an "X" in the appropriate box to show how you are affected by using the

 (device name).

	Decreases -3	-2	-1	0	1	2	3 Increases
1) Competence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2) Happiness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3) Independence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4) Adequacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5) Confusion	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6) Efficiency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7) Self-esteem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8) Productivity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9) Security	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10) Frustration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11) Usefulness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12) Self-confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13) Expertise	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14) Skillfulness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15) Well-being	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16) Capability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17) Quality of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18) Performance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19) Sense of Power	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20) Sense of control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21) Embarrassment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22) Willingness to take chances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23) Ability to participate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24) Eagerness to try new things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25) Ability to adapt to the activities of daily living	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26) Ability to take advantage of opportunities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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☐ COMPLETE

### PIADS SCORING SHEET

Enter Client ID# and the device being rated in the white spaces below.

**Client  
ID#:**

**Device:**

Enter the value selected for each item on the PIADS in the "Item Score" column. Subscale scores are calculated automatically and inserted in the "Subscale Score" column. Appropriate values will range from -3 to +3.

Item Number	Item	Item Score
1	Competence	2
2	Happiness	3
3	Independence	
4	Adequacy	
5	Confusion	
6	Efficiency	
7	Self-esteem	
8	Productivity	
9	Security	
10	Frustration	
11	Usefulness	
12	Self-confidence	
13	Expertise	
14	Skillfulness	
15	Well-being	
16	Capability	
17	Quality of life	
18	Performance	
19	Sense of power	
20	Sense of control	
21	Embarrassment	
22	Willingness to take chances	
23	Ability to participate	
24	Eagerness to try new things	
25	Ability to adapt to the activities of daily living	
26	Ability to take advantage of opportunities	

#### Subscale Scores

Competence	0,00
Adaptability	0,00
Self-Esteem	0,00

## **APPENDIX 2:**

### **FEW, FEW-P & FEW-C**

# Functioning Everyday with a Wheelchair (FEW)

Subject Code: \_\_\_\_\_

**DIRECTIONS:** Please answer the following 10 questions by placing an 'X' in the box under the response (completely agree, mostly agree, slightly agree, etc.) that best matches your ability to function while in your wheelchair/scooter. All examples may not apply to you, and there may be tasks you perform that are not listed. Mark each question only one time, if you answer, "slightly," "mostly," or "completely disagree for any question, please circle the feature(s) (i.e., size, fit, postural support, functional) contributing to your disagreement, and write the reason for your disagreement in the Comments section.

	Completely Agree	Mostly Agree	Slightly Agree	*Slightly Disagree	*Mostly Disagree	*Completely Disagree	Does not apply
<b>1. The stability, durability and dependability features of my wheelchair/scooter contribute to my ability to carry out my daily routines as independently, safely and efficiently as possible:</b> <i>(e.g., tasks I want to do, need to do, am required to do- when and where needed)</i>							
<b>Comments:</b>							
<b>2. The size, fit, postural support and functional features of my wheelchair/scooter match my comfort needs as I carry out my daily routines:</b> <i>(e.g., heel/moisture, sitting tolerance, pain, stability)</i>							
<b>Comments:</b>							
<b>3. The size, fit, postural support and functional features of my wheelchair/scooter match my health needs:</b> <i>(e.g., pressure sores, breathing, edema control, medical equipment)</i>							
<b>Comments:</b>							
<b>4. The size, fit, postural support and functional features of my wheelchair/scooter allow me to operate it as independently, safely, and efficiently as possible:</b> <i>(e.g., do what I want it to do when and where I want to do it)</i>							
<b>Comments:</b>							
<b>5. The size, fit, postural support and functional features of my wheelchair/scooter allow me to reach and carry out tasks at different surface heights as independently, safely, and efficiently as possible:</b> <i>(e.g., table, counters, floors, shelves)</i>							
<b>Comments:</b>							
<b>For questions #2 thru #10:</b> <b>size</b> (e.g., wheelchair and seating frame- width, length, height) <b>fit</b> (e.g., not too large, not too small, allows desired movement) <b>postural support</b> (e.g., provides support, stability, and control for the body- bones, muscles, and tissues) <b>functional</b> (e.g., speed, wheels, cushion, controller, backrest, legrests, seat belt, tilt/recline system, seat elevator, laptray, basket, cane holder, horn, lights)							



Subject Code: \_\_\_\_\_

6. The size, fit, postural support and functional features of my wheelchair/scooter allow me to transfer from one surface to another surface as independently, safely, and efficiently as possible:  
(e.g., bed, toilet, chair)

Comments:

7. The size, fit, postural support and functional features of my wheelchair/scooter allow me to carry out personal care tasks as independently, safely, and efficiently as possible:  
(e.g., dressing, bowel/bladder care, eating, hygiene)

Comments:

8. The size, fit, postural support and functional features of my wheelchair/scooter allow me to get around indoors as independently, safely, and efficiently as possible:  
(e.g., home, work, mall, restaurants, ramps, obstacles)

Comments:

9. The size, fit, postural support and functional features of my wheelchair/scooter allow me to get around outdoors as independently, safely, and efficiently as possible:  
(e.g., uneven surfaces, dirt, grass, gravel, ramps, obstacles)

Comments:

10. The size, fit, postural support and functional features of my wheelchair/scooter allow me to use personal or public transportation as independently, safely, and efficiently as possible:  
(e.g., secure, slow, ride)

Comments:

For questions #2 thru #10:

size (e.g., wheelchair and seating frame- width, length, height)

fit (e.g., not too large, not too small, allows desired movement)

postural support (e.g., provides support, stability, and control for the body- bones, muscles, and tissues)

functional (e.g., speed, wheels, cushion, controller, backrest, legrests, seat belt, tilt/recline system, seat elevator, laptray, basket, cane holder, horn, lights)

Cholin, Mills, Schneider, &amp; Treiber, 2003

## Therapist Task Guide: 10 FEW-Capacity (FEW-C)

### Task # 1: Stability, Durability, and Dependability

- Mark type of mobility device used by consumer and if s/he has had current wheelchair/scooter for less than 1 month on the 1<sup>st</sup> task instruction sheet
- For stability items 1 a–e, durability items 2 a–b, and dependability items 3 a–b, see individual task instruction sheets for therapist task guide.

### Task # 2: Comfort Needs

- **Comfort Method I:** Describe one method you use to improve your comfort, and show me how you do it. (First have consumer describe, and then demonstrate how s/he improves comfort -- write consumer response (method) and feature(s) used in provided space)
- **Comfort Method II:** Describe another method you use to improve your comfort, and show me how you do it. (First have consumer describe, and then demonstrate how s/he improves comfort -- write consumer response (method) and feature(s) used in provided space)

### Task # 3: Health Needs

- **Weight Shift:** Describe one method you use to shift your weight, and show me how you do it. (First have consumer describe, and then demonstrate how s/he weight shifts -- write consumer response (method) and feature(s) used in provided form)
- **Leg Elevation**
  - Do you typically elevate your legs. (Mark 'Yes', 'No', or 'Not applicable')
  - If 'No' or 'Not applicable', describe why. (Write reason why consumer does not perform leg elevation while seated in wheelchair/scooter on provided form) If you were to elevate your legs, describe what you would do, and show me how you do it. (First have consumer describe, and then demonstrate how s/he would perform leg elevation -- write consumer response (method) and feature(s) used on the provided form)
  - If 'Yes', describe method you use to elevate your legs, and show me how you do it. (First have consumer describe, and then demonstrate how s/he performs leg elevation -- write consumer response (method) and feature(s) used on the provided form)

You will need to mark 'does elevate' or 'does not elevate' on the provided form in order to identify if the recorded information is for a consumer who responded 'Yes' or 'No' to performing leg elevation.
- **Medical/ Health-related (MHR) Function**
  - Usually performs or needs to perform medical/health-related function(s) while seated in wheelchair/scooter. (Mark 'Yes', 'No', or 'Not applicable')
  - Carries/stows any medication or medical equipment/devices with you when using wheelchair/scooter. (Mark 'Yes', 'No', or 'Not applicable')
  - If yes, describe what it is or what you do. (Write consumer response on provided form)
  - Show me how you perform this function, and/or retrieve, use, and stow your medicine/medical equipment/devices while seated in your wheelchair/scooter. (Write method and feature(s) used on provided form. Task performance may not be feasible, or therapist/consumer may determine that task(s) cannot be safely and reasonably carried out)

#### **Task # 4: Operate Wheelchair/Scooter**

- Clinic/laboratory area with consumer seated in wheelchair/scooter typically used to perform tasks, and positioned next to therapist.
- "Prior to starting, therapist will identify an area that is 8 ft in length with a 90° turn to the L or R and a 6 ft long path (all having a minimum of 36" in width (e.g., a hallway with a turn; an unobstructed open clinic/laboratory space)).
- A left or right course diagram is included for this task (see Task #4 Diagram).
- Write a description of the location, route, and feature(s) used for task performance in the provided space.
- **Starting from "this location"** *[Point to where therapist and consumer are standing -- choose a location with a path of least resistance, and a travel distance of at least 12 feet (e.g., vertical length of two doors)]*
- **You can carry it with you, but I will provide step-by-step directions along the way** *[Provide copy of course diagram (left or right) to consumer if they choose]*
- **Position your wheelchair/scooter facing "this direction"** *[Indicate direction consumer should face -- wait for consumer to assume position]*
- **Travel forward to that corner ["this point/location"] and make a ["right turn or left turn"]** *[Indicate point/location where consumer should make right or left turn]*
- **Continue traveling forward until you get to "this point/" location, then without turning your wheelchair/scooter around, travel in reverse back to "here"** *[Indicate direction consumer should travel and point/location where s/he should stop, then instruct consumer to travel in reverse and indicate point/location where s/he should stop]*
- **Turn off wheelchair/scooter or lock brakes** *[Wait for consumer to turn off wheelchair/scooter or lock brakes]*
- **Turn wheelchair/scooter back on or unlock your brakes** *[Wait for consumer to turn on wheelchair/scooter or unlock brakes]*
- **Turn around going in "this direction" [right turners = counterclockwise direction; left turners = clockwise direction]** *[Indicate or demonstrate direction consumer should turn -- wait for consumer to complete turn in wheelchair/scooter]*
- **Return to "where we started and stop"** *[Indicate starting point/location where consumer should travel to -- wait for consumer to return to starting location]*

#### **Task # 5: Reach and Carry Out Tasks at Different Surface Heights**

- For each subtask write a description of the item, location, and feature(s) used for subtask performance in the provided space.
- Clinic/laboratory area, table/counter/desktop and drawer/cupboard nearby with consumer seated in wheelchair/scooter typically used to perform task, and positioned next to therapist.
- Common items in the clinic/laboratory will be used for this task. Each item must not exceed a maximum weight of 2 pounds (e.g., bag of beans, stapler), and a maximum size of 12" x 12" inches (e.g. box of cereal, 3 ring binder).
- Prior to starting, therapist will survey the area, and identify locations and items for each subtask.
- **First have consumers describe how they would perform subtask, and then ask them to show you:**

- Retrieve the    from here [Point to item on surface above subject's (Ss) shoulder height – within Ss arm's length] and then place it here [Point to surface at Ss shoulder level – directly below area where item was retrieved]
- Retrieve the    from here [Point to item far back in drawer/counter top – at Ss shoulder level] and then hand it to me [Therapist holds out hand, palm up, approximately arm's length away from Ss -- at the same height as the drawer/counter top, but on opposite side Ss used to retrieve item]
- Retrieve the    [Point to item on floor] and then place it here [Point to nearby countertable surface at Ss shoulder level -- just beyond Ss arm length]

#### Task # 6: Transfers

- For each subtask, write a description of the transfer surface, location, and feature(s) used in the provided space.
- Clinic/labouratory area with consumer seated in wheelchair/scooter typically used to perform task, and positioned next to therapist
- Two transfer surfaces will be used for this task: "easy transfer = same level as consumer's seated surface" and "complex transfer = 3' above or 3' below consumer's seated surface."
- Prior to starting, therapist will survey the area, and identify locations for each transfer surface. [Adjustable height exam/mat tables can be used for both tasks]
- Mark "3' above" or "3' below" to indicate what type of complex transfer was performed on both the task instruction sheet and the scoring form.
- First have consumers describe how they would perform subtask, and then ask them to show you:
  - (Easy and Complex) Place your wheelchair/scooter in the position you would typically use for this transfer [Wait for consumer to position wheelchair/scooter]
  - (Easy and Complex) Transfer from your wheelchair/scooter to    [Wait for consumer to perform transfer -- if assistance is requested or needed, be sure to enter on score sheet]
  - (Easy and Complex) Transfer back to your wheelchair/scooter [Wait for consumer to perform transfer -- if assistance is requested or needed, be sure to enter on score sheet]

#### Task # 7: Personal Care Tasks

- Clinic/labouratory area, sink nearby with consumer seated in wheelchair/scooter typically used to perform tasks, and positioned next to therapist.
- Shirt/coat/jacket will be available for consumer use or consumer can use own clothing. The clothing item can either be an open front or pull-over garment.
- The hand washing items available in the clinic/labouratory area (e.g., nearby bathroom) will be used, but therapist will also have items available for consumer use.
- First have consumers describe how they would perform subtask, and then ask them to show you:
  - Upper Body Dressing**
    - Mark whether a shirt/coat/jacket provided by therapist or consumers' shirt/coat/jacket was used for subtask performance on the task instruction sheet. If consumers' shirt/coat/jacket was used, write a brief description of the item, location, and feature(s) used in the provided space.

- **Put on the shirt/coat/jacket** *[Wait for consumer to don shirt/coat/jacket including fastening buttons, zippers, velcro, etc... if typically done]*
- **Take off the shirt/coat/jacket** *[Wait for consumer to doff shirt/coat/jacket]*

#### **Personal Hygiene**

- Mark whether personal hygiene products provided by therapist or products available in clinic or laboratory area were used for subtask performance on the task instruction sheet. Write the location and feature(s) used for subtask performance in the provided space.
- **Wash your hands with soap, and then rinse and dry them** *[Wait for consumer to wash, rinse, and dry hands -- if items typically used are not available in clinic or laboratory, therapist will provide needed items, and place them in respective locations]*

#### **Task #5: Indoor Mobility**

- Write a description of the location, route, door, and feature(s) used for subtask performance for the carpeted and non-carpeted course in the provided space on the task instruction sheet and/or the provided form if additional space is needed.
- Clinic/laboratory area with consumer seated in wheelchair/scooter typically used to perform task, and positioned next to therapist.
- \*Prior to starting, therapist will survey the area, and identify locations for each subtask -- including carpeted and non-carpeted surfaces large enough to make a 90° turn (minimum), and a doorway wide enough to accommodate a wheelchair -- and a door equipped with a lever handle or knob
- **(Carpeted and Non-carpeted Surface) Starting from here** *[Point to where therapist and consumer are standing -- choose a location with a one way travel distance of at least 12 feet (e.g., vertical length of two doors). The course should take the consumer over both a carpeted and non-carpeted surface]*
- **(Carpeted and Non-carpeted Surface) Travel in "this direction, make a turn at "this point/location, and then open and go through "that door and close it behind you** *[Indicate direction consumer should travel, point/location for turn and the door to enter -- wait for consumer to enter and then close door]*
- **(Carpeted and Non-carpeted Surface) Open the door, come out, and close the door behind you. Then return to where you started following the same course and then stop** *[Wait for consumer to open door, come out, and close the door, and then return to starting location]*

#### **Task #6: Outdoor Mobility**

- Write a description of the location, terrain, and feature(s) used for subtask performance in the provided space on the task instruction sheet and/or on the provided form if additional space is needed.
- Outdoor clinic/laboratory area with consumer seated in wheelchair/scooter typically used to perform task, and positioned next to therapist.
- \*Prior to starting, therapist will have identified a 3 block (1/4 mile) route that includes flat easy terrain, an inclined terrain, curb cuts and flat difficult (uneven) terrain
- Mark whether a sidewalk, curb cut, or terrain transition (e.g., even to uneven ground, grass to sidewalk) was used for subtask #2 on the task instruction sheet and the scoring form
- **(Flat Easy Terrain) Starting from here** *[Point to where therapist and consumer are standing -- choose a flat location with easy (i.e., concrete/solid ground) terrain to negotiate]*

- **(Flat Easy Terrain)** Travel to **\*this point/location**, and then turn around and return to where you started. [Indicate direction and \*point/location where consumer should travel to -- wait for consumer to get to point/location, turn around, and return to starting location]
- **(Inclined Easy Terrain)** Starting from here. [Allow time for therapist and consumer to move in base of inclined surface (ADA compliant ramp -- 1:"2 ratio -- at least 6 feet long) -- choose an inclined surface with easy (i.e., concrete/solid ground) terrain to negotiate]
- **(Inclined Easy Terrain)** Travel to **\*this point/location**, and then turn around and return to where you started. [Indicate direction and \*point/location where consumer should travel to -- wait for consumer to get to point/location, turn around, and return to starting location]
- **(Curb Cut/Sidewalk/Terrain Transition)** Starting from here. [Allow time for therapist and consumer to move to curb cut/sidewalk/terrain transition -- choose a curb cut/sidewalk with a low to medium grade (< 6 inches in height; e.g., length of step)]
- **(Curb Cut/Sidewalk/Terrain Transition)** Go down **\*this curb cut/sidewalk**, and then turn around and come back up the curb cut/sidewalk, or negotiate over terrain transition. [Indicate \*curb cut/sidewalk/terrain transition for consumer to negotiate -- wait for consumer to negotiate down curb cut/sidewalk, turn around, and negotiate up curb cut/sidewalk, or over terrain transition]
- **(Flat Difficult Terrain)** Starting from here. [Allow time for therapist and consumer to move to location -- choose a flat location with difficult (e.g., grass, dirt, gravel) terrain to negotiate]
- **(Flat Difficult Terrain)** Travel to **\*this point/location**, and then turn around and return to where you started. [Indicate direction and \*point/location where consumer should travel to -- wait for consumer to get to point/location, turn around, and return to starting location]

#### **Task # 10: Personal/Public Transportation**

- (Self-report component) Complete both the personal transportation items 5 a-d, and public transportation items 4 a-d. See individual task instruction sheets for therapist task guide.
- Mark 'Yes', or 'No' to indicate if subtask performance was or was not completed for personal transportation and public transportation on the task instruction sheet and the scoring form.
- Write a description of the location, type of vehicle, and vehicle and wheelchair/scooter feature(s) used for subtask performance in the provided space and/or on the provided form if additional space is needed.
- Begin in clinic/laboratory area with consumer seated in wheelchair/scooter typically used to perform task and positioned next to therapist.
- First have consumers describe how they would perform subtask, and then ask them to show you:
  - Personal Transportation**
    - **Take me to the vehicle you use for personal transportation.** [Follow consumer and allow time for s/he to get to vehicle]
    - **Show me how you and your wheelchair/scooter get in the vehicle, and then how you secure yourself and your wheelchair/scooter for transportation.** [Wait for consumer and wheelchair/scooter to get into the vehicle, and be secured for transportation]
    - **Show me how you and your wheelchair/scooter get out of the vehicle.** [Wait for consumer to get out/unload wheelchair/scooter from vehicle]
  - For the **public transportation task**, the following guidelines apply: (1) for ACCESS or other accessible public transportation vehicle -- ask the driver to allow the consumer to show how s/he boards, secures and

unsecures self/wheelchair or scooter, and exits the vehicle; or (2) for a Port Authority or other public transportation vehicle - the examiner should board the vehicle first and inform the driver that you and consumer will be traveling only 2 stops and if he/she could assist by not charging a fare to the consumer --- otherwise pay the fare, travel 2 stops, and exit the vehicle.

- **For the public transportation task** depending on the situation, it is possible that this task will occur twice (i.e., traveling to and returning from a location). If subtask/task performance occurs twice, the examiner should give a cumulative subtask/task score (independence, safety, and quality) for overall consumer performance.
- **First have consumers describe how they would perform subtask, and then ask them to show you:**  
**Public Transportation**
  - **Take me [follow me] to where you would catch a bus/van, or meet a public transportation vehicle** *[Follow/guide consumer and allow time for s/he to get to location]*
  - **Show me how you get on the bus/van, and how you usually secure yourself and your wheelchair/scooter while riding the bus/van** *[Wait for consumer to get into the bus/van, and secure self and wheelchair/scooter]*
  - **Show me how you exit the bus/van in your wheelchair/scooter** *[Wait for consumer to get off the bus/van]*

#### Therapist Task Guide: 10 FEW-Performance {FEW-P} Tasks

##### Task # 1: Stability, Durability, and Dependability

- See FEW-C task (p. 14).

##### Task # 2: Comfort Needs

- See FEW-C task (p. 14).

##### Task # 3: Health Needs

- See FEW-C task (p. 14).

##### Task # 4: Operate Wheelchair/Scooter

- Living/work area with consumer seated in wheelchair/scooter typically used to perform tasks, and positioned next to therapist.
- Prior to starting, therapist will survey the living/work area, and identify locations for each subtask, if necessary, ask for consumer assistance/input in selecting subtask locations.
- A left or right course diagram is included for this task (see Task #4 Diagram).
- Write a description of the location, route, and feature(s) used for task performance in the provided space.
- See FEW-C task (p. 15).

#### **Task # 5: Reach and Carry Out Tasks at Different Surface Heights**

- For each subtask, write a description of the item, location, and feature(s) used for subtask performance in the provided space.
- Living/work area, table/counter/desk, and drawer/cupboard nearby with consumer seated in wheelchair/scooter typically used to perform task, and positioned next to therapist.
- Items in the consumer's living/work area will be used for this task. Each item must not exceed a maximum weight of 7 pounds (e.g. bag of beans, stapler), and a maximum size of 12" x 12" inches (e.g. box of cereal, 3-ring binder).
- Prior to starting, therapist will survey the living/work area, and identify locations and items for each subtask.
- See FEW-C task (p. 15).

#### **Task # 6: Transfers**

- For each subtask, write a description of the transfer surface, location, and feature(s) used in the provided space.
- Living/work area with consumer seated in wheelchair/scooter typically used to perform task, and positioned next to therapist.
- Depending on the environment and availability of transfer surfaces, two transfer surfaces will be used for this task: "easy transfer = same level as consumer's seated surface" and "complex transfer = 3" above or 3" below consumer's seated surface.
- Prior to starting, therapist will survey the living/work area, and identify locations for each subtask, as well as ask for consumer assistance/input in selecting two transfer surfaces.
- See FEW-C task (p. 16).

#### **Task # 7: Personal Care Tasks**

- Living/work area, sink nearby with consumer seated in wheelchair/scooter typically used to perform tasks, and positioned next to therapist.
- Items in the consumer's living/work area will be used for this task; however, therapist will also have necessary items available for each task.
- Shirt/coat/jacket will be available for consumer use or consumer can use own clothing. The clothing item can either be an open front or pull over garment.
- If a consumer uses the shirt/coat/jacket provided by the therapist, ask where this item of clothing is typically kept or placed, and place the item here for consumer to retrieve.
- First have consumers describe how they would perform subtask, and then ask them to show you:
  - Upper Body Dressing**
    - Mark whether a shirt/coat/jacket provided by therapist or consumer's shirt/coat/jacket was used for subtask performance on the task instruction sheet. If consumer's shirt/coat/jacket was used, write a brief description of the item, location, and feature(s) used in the provided space.
    - I have one that you can use** [Ask consumer where s/he would typically keep a shirt/coat/jacket. Place shirt/coat/jacket in that location – wait for consumer to retrieve shirt/coat/jacket.]
    - **Put on the shirt/coat/jacket** [Wait for consumer to don shirt/coat/jacket including fastening buttons, zippers, velcro, etc., if typically done.]
    - **Take off the shirt/coat/jacket** [Wait for consumer to doff shirt/coat/jacket.]



#### **Personal Hygiene**

- Mark whether personal hygiene products provided by therapist or products available in clinic or laboratory area were used for subtask performance on the task instruction sheet. Write the location and feature(s) used for subtask performance in the provided space.
- *Take me to where you would usually wash your hands. (If allow consumer and wait for s/he to get to location)*
- *Wash your hands with soap, and then rinse and dry them. (Wait for consumer to wash, rinse, and dry hands -- If items typically used are not available, therapist will provide needed items, and place them in respective locations)*

#### **Task #8: Indoor Mobility**

- Write a description of the location, route, floor, and feature(s) used for subtask performance for the carpeted and non-carpeted course in the provided space on the task instruction sheet and/or the provided form if additional space is needed.
- Living/work area with consumer seated in wheelchair/scooter typically used to perform task, and positioned next to therapist.
- \*Prior to starting, therapist will survey the living/work area, and identify locations for each subtask, as well as ask for consumer assistance/input in selecting a carpeted and non-carpeted surface.
- See FEW-C task (p. 17).

#### **Task #9: Outdoor Mobility**

- Write a description of the location, terrain, and feature(s) used for subtask performance in the provided space on the task instruction sheet and/or on the provided form if additional space is needed.
- Mark whether a sidewalk, curb cut, or terrain transition (e.g., even to uneven ground, grass to sidewalk) was used for subtask #3 on the task instruction sheet and the scoring form.
- Outdoor living/work area with consumer seated in wheelchair/scooter typically used to perform task and positioned next to therapist.
- \*Prior to starting, therapist will survey the outdoor living/work area, and identify locations for each subtask, as well as ask for consumer assistance/input in selecting task location. The distance for this task should be at least 3 blocks or 1/4 mile, and includes flat easy terrain, inclined terrain, curb cuts/sidewalks/terrain transitions, and flat difficult (uneven) terrain.
- The Inclined easy terrain should be at least 6 feet long, but it does not have to be ADA compliant.
- See FEW-C task (p. 17).

#### **Task #10: Personal/Public Transportation**

- (Self-report component) Complete both the personal transportation items 3 a-f, and public transportation items 4 a-d. See individual task instruction sheets for therapist task guide.
- Mark 'Yes' or 'No' to indicate if subtask performance was or was not completed for personal transportation and public transportation on the task instruction sheet and the scoring form.
- Write a description of the location, type of vehicle, and vehicle and wheelchair/scooter feature(s) used for subtask performance in the provided space and/or on the provided form if additional space is needed.

- Begin in living/work area with consumer seated in wheelchair/scooter typically used to perform task and positioned next to therapist.
- First have consumers describe how they would perform subtask, and then ask them to show you.
  - Personal Transportation**
    - Take me to a vehicle you use for personal transportation. *[Follow consumer and allow time for s/he to get to vehicle.]*
    - Show me how you and your wheelchair/scooter get in the vehicle, and then how you secure yourself and your wheelchair/scooter for transportation. *[Wait for consumer and wheelchair/scooter to get into the vehicle, and to be secured for transportation.]*
    - Show me how you and your wheelchair/scooter get out of the vehicle. *[Wait for consumer to get out/unload wheelchair/scooter from vehicle.]*
- For the public transportation task, the following guidelines apply: (1) for ACCESS or other accessible public transportation vehicle -- ask the driver to allow the consumer to show how s/he boards, secures and unsecures self/wheelchair or scooter, and exits the vehicle; or (2) for a port authority or public transportation vehicle -- the examiner should board the vehicle first and inform the driver that you and consumer will be traveling only 2 stops and if he/she could assist by not charging a fare to the consumer -- otherwise pay the fare, travel 2 stops, and exit the vehicle.
- For the public transportation task, depending on the situation, it is possible that this task will occur twice (i.e., traveling to and returning from a location). If subtask/task performance occurs twice, the examiner should give a cumulative subtask/task score (independence, safety, and quality) for overall consumer performance.
- First have consumers describe how they would perform subtask, and then ask them to show you:
  - Public Transportation**
    - Take me to where you would typically catch a bus/van, or meet a public transportation vehicle. *[Follow consumer and allow time for s/he to get to location.]*
    - Show me how you get on the bus/van, and how you usually secure yourself and your wheelchair/scooter while riding the bus/van. *[Wait for consumer to get into the bus/van, and secure self and wheelchair/scooter.]*
    - Show me how you exit the bus/van in your wheelchair/scooter. *[Wait for consumer to get off the bus/van.]*

-A 6566

## **APPENDIX 3:**

### **WSC**

WHEELCHAIR SPECIFICATIONS: A CHECKLIST.

Name:

Age:

Contact nr:

Address:

Diagnosis:

Period wheelchair bound:

Period in current wheelchair:

Date of last seating clinic/ wheelchair check up:

Amount of time spent in wheelchair daily/ Uses of wheelchair:

Description of environment:

Transport:

Pressure sores history: Y/N

If Yes: area, frequency:

Home visit: YIN

Describe current wheelchair/ tick appropriate on order form (see attached).  
(order form as used by EC when prescribing)

Name:	Surname:	Options		
		1	2	3
(1) (MILK FEEDING)		Complete different size	Same as in previous	Same size
(2) (MILK)		Not enough	Suitable to one area of p's life i.e. udder, hind legs only	Suitable to all areas of p's life
(3) (MILK)		MLC reduces p's functional ability	MLC doesn't promote/induce p's functional ability	MLC promotes p's functional ability
(4) (MILK)		No practical support provided	Support provided but inadequate	Adequate support provided
(5) (MILK)		Not adequate	Taken into account but to limited extent i.e. not fully met	Suitable and adequate
(6) (MILK POSTURE)				

(1) Lactating everyday with water etc.  
 (2) Lactating everyday with water etc. (see above)  
 (3) Lactating everyday with water etc. (see above)

## **APPENDIX 4: SEMI-STRUCTURED INTERVIEW**

### **GUIDELINE OF QUESTIONS**

#### **Experience and Training:**

- Have you had any form of training in seating? If yes, please explain what type and when.
- Off the top of your head, which wheelchairs are currently available on tender for adult clients?
- Why do you prescribe wheelchairs for clients?
- Do you ever feel it unnecessary to order a wheelchair and if yes please explain?
- What are some of the experiences you have had in the past that have had an influence on the way you prescribe wheelchairs now? Positive/ Negative

#### **Prescription:**

- Which tender wheelchair do you prescribe most and why?
- When prescribing a wheelchair for a client, where do you normally start?
- Please explain your evaluation procedure.
- What are some of the things you consider when prescribing a wheelchair?
- Do you feel that a wheelchair needs to be appropriate and specific to every area of a client's life?
- Do you think this is possible with the current wheelchairs available on tender?
- Do you ever feel it necessary to order a client a wheelchair that doesn't exactly fit their lifestyle and environment and if yes, please explain?
- What is your knowledge/ understanding about the Eastern Cape's procurement process?
- How do you feel about the Eastern Cape's procurement process?
- Does the procurement process influence your prescription and if yes please explain.
- Do the clients need to pay for their wheelchairs or for any service to the wheelchair?

#### **Challenges:**

- How do you feel about wheelchairs and seating?
- What are some of the challenges you experience when prescribing a wheelchair?
- How do you compensate or try to overcome these challenges, if anything?
- How long does it normally take from prescription to delivery?

- Is this a problem?

**Ideal wheelchair:**

- What are some of the things you think a wheelchair should do for a client?
- In your experience, what do clients want most out of their wheelchair?
- In your experience, what do clients complain about most with regards to their wheelchair?

## **APPENDIX 5:**

### **DoH APPROVAL**



2 Matopos  
68 Park Drive  
Central  
Port Elizabeth  
6001  
10<sup>th</sup> August 2012

Mrs. K Moodaley  
Head of Department  
Physiotherapy Department  
PEHC

Dear Mrs Moodaley

RE: Permission to carry out research for thesis at PEHC and the western region of the Eastern Cape as part of my Masters Degree in Physiotherapy

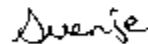
I am currently enrolled at Stellenbosch University for a Masters Degree in Physiotherapy. Due to technical delays, I have not initiated the research component of my thesis. I am hereby requesting permission to do so within the PEHC and the Western Region of the Eastern Cape.

This research encompasses the efficiency and reliability of wheelchair issuing by therapists in this region and will look at possible avenues of assistance to improve this service. This information will therefore be of great benefit to our therapists, rehabilitation managers and rehabilitation departments as a whole in the Eastern Cape. It will not only improve our standard of treatment, but work towards incorporating core principles of Batho Pele into Consultation and Service Standards.

Please feel free to contact me for any clarification or further information that you may require.

Thank you

Regards,



Mrs S Duffield



**EASTERN CAPE DEPARTMENT OF HEALTH**

**PE HOSPITAL COMPLEX**

Gora Nginza Hospital, Spondo Street, Zwile  
PORT ELIZABETH, 6057, South Africa

Tel no.: 041 408 4211/4202  
@impilo.ecprov.gov.za

E-mail : nazley.fakir

October 2012

To Mrs Duffield  
Physiotherapy Student

To Mrs M. Thomas  
Chief Physiotherapist  
PEHC

RE: Permission to carry out research for thesis at PEHC and the western region of the Eastern Cape as part of my Masters Degree in Physiotherapy

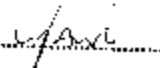
I have no objection with you ,Mrs Duffield, doing your study at DNH.

On completion of your study, you are requested to please submit a copy of to the Medical Superintendent of DNH in which your research was performed, for record purposes as well as the Chief Physiotherapist of DNH.

We wish you all the best with your research.

Thank you

Sincerely

  
**Miss N. Fakir**  
Acting Hospital Manager  
NF/wk

DR. C. SUPERINTENDENT  
GORA NGINZA HOSPITAL  
PORT ELIZABETH  
ALONG PARK ROAD

**RAHMO PALL**  
ABANGA KLODALL PEOPLE FIRST

## **APPENDIX 6 PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

**TITLE OF THE RESEARCH PROJECT:  
WHEELCHAIR PRESCRIPTION IN THE WESTERN REGION OF THE EASTERN  
CAPE.**

**REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR: S. DUFFIELD**

**ADDRESS: 2 MATOPOS**

**68 PARK DRIVE**

**CENTRAL**

**PORT ELIZABETH**

**6001**

**CONTACT NUMBER:041 405 2261**

**041 373 2666**

**083 277 9568**

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the

study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### **What is this research study all about?**

Through this study we want to find out if the wheelchair you have is right for where you live, what you do everyday and the way your body is built. We also want to find out why and how therapists get wheelchairs for their clients. This part of the study has two short questionnaires which you will be asked to fill in with the help of a translator and/ or someone to write for you if you need it. After the questionnaires you will be measured again for a wheelchair and asked to perform simple actions in your wheelchair. You will not be asked to do anything in your wheelchair that you know you can't do.

### **Why have you been invited to participate?**

You are one of 30 participants who have been asked to help us with this study because you got your wheelchair through the public health system and you have been using it for more than three months, which means you should be able to answer our questions.

### **What will your responsibilities be?**

You will be asked to fill in 2 questionnaires with someone's help if you need it. You will then be asked to perform a couple of simple actions in your wheelchair that will be explained to you clearly. This will take about an hour and a half of your time.

### **Will you benefit from taking part in this research?**

Though you might not directly benefit from taking part in this study, you will contribute to wheelchair service delivery in the Eastern Cape. Your contribution could bring about major changes to the way wheelchairs are prescribed for persons with disabilities.

**Are there any risks involved in your taking part in this research?**

There are no foreseeable risks involved in taking part in this study.

**If you do not agree to take part, what alternatives do you have?**

If you choose not to take part in this study but would like to be re-evaluated for a wheelchair, you can get in touch with your local physio-/ occupational therapist via the clinic who will assist you with a re-evaluation. Also, if you don't want to be a part of the study anymore, you can drop out at any time without any consequences.

**Who will have access to your medical records?**

All information collected will be treated as confidential and protected. Only the researcher and the research assistant/ translator will have access to your information. If any of the information is to be used in a publication or thesis, your identity will remain **anonymous** at all times. The records may be inspected by other agencies for auditing purposes – in which instance your identity will also remain anonymous.

**Will you be paid to take part in this study and are there any costs involved?**

No you will not be paid to take part in the study. If you are asked to come to the clinic for the study all your transport costs will be covered. There will be no costs involved for you, if you do take part.

**Is there anything else that you should know or do?**

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled:

**Wheelchair prescription in the Eastern Cape: the need for a closer look.**

**I declare that:**

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.

I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) ..... 2005.

.....  
**Signature of participant**

.....  
**Signature of witness**

#### **Declaration by investigator**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 2005.

.....  
**Signature of investigator**

.....  
**Signature of witness**

**Declaration by interpreter**

I (*name*) ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) ..... using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ..... on (*date*) .....

.....  
**Signature of interpreter**

.....  
**Signature of witness**

## **PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**

### **TITLE OF THE RESEARCH PROJECT:**

**WHEELCHAIR PRESCRIPTION IN THE EASTERN CAPE: THE NEED FOR A CLOSER LOOK.**

### **REFERENCE NUMBER:**

**PRINCIPAL INVESTIGATOR: S. DUFFIELD**

**ADDRESS: 2 MATOPOS  
68 PARK DRIVE  
CENTRAL  
PORT ELIZABETH  
6001**

**CONTACT NUMBER: 041 405 2261  
041 373 2666  
083 277 9568**

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### **What is this research study all about?**

This study is about wheelchair prescriptions in the Eastern Cape. During the first part of the study, wheelchair users were assessed and asked about their perceived level of satisfaction with their wheelchair. The therapists prescribed the wheelchairs for the patients who participated in the first part of the study, have been invited to take part in this study.

This study aims to see whether or not wheelchair users are satisfied with their wheelchairs, and if they have been given the right wheelchair for their lifestyle and capabilities. This project aims to find out why and how therapists order wheelchairs for



their clients, as well as the challenges and barriers therapists face in this part of the Eastern Cape.

For this section which includes you as a therapist, a semi structured interview will be conducted where simple questions into wheelchair prescriptions will be asked. This will only take about 30 minutes of your time and will be done either at your place of work or over the telephone, whatever is more convenient for you.

**Why have you been invited to participate?**

You have been asked to participate because you are currently working and prescribing wheelchairs in the Western Region of the Eastern Cape and have prescribed a wheelchair for one/ more of the participants of the first part of the study

**What will your responsibilities be?**

You will be asked to share your perspectives about wheelchair prescription and answer a couple of simple questions as honestly and clearly as you can

**Will you benefit from taking part in this research?**

Though you might not directly benefit from taking part in this study, you will contribute to wheelchair service delivery in the Eastern Cape. Your contribution could bring about major changes to the way wheelchairs are prescribed to persons with disabilities.

**Are there any risks involved in your taking part in this research?**

There are no foreseeable risks involved in this study.

**Who will have access to your information/ answers?**

All information collected will be treated as confidential and protected. Only the researcher and the research assistant/ translator will have access to your information. If any of the information is to be used in a publication or thesis, **your identity will remain anonymous** at all times.

**Will you be paid to take part in this study and are there any costs involved?**

No you will not be paid to take part in the study, but there will also be no cost involved for you to take part in the study.

**Is there any thing else that you should know or do?**

You can contact Ms. S. Duffield at 041 373 2866 if you have any further queries or encounter any problems.

You can contact the Health Research Ethics Committee at 021 938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.

You will receive a copy of this information and consent form for your own records.

### Declaration by participant

By signing below, I ..... agree to take part in a research study entitled:

**Wheelchair Prescription in the Eastern Cape: the need for a closer look.**

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressured to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) .....

.....  
**Signature of participant**

.....  
**Signature of witness**

### Declaration by investigator

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.
- I did/did not use an interpreter.

Signed at (*place*) ..... on (*date*) ..... 2013.

.....  
**Signature of investigator**

.....  
**Signature of witness**

**Declaration by interpreter**

I (*name*) ..... declare that:

- I assisted the investigator (*name*) ..... to explain the information in this document to (*name of participant*) ..... , using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ..... on (*date*) .....

.....  
**Signature of interpreter**

.....  
**Signature of witness**